

DEATH AND DYING IN A HOSPICE :  
AN ETHNOGRAPHIC STUDY

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## DECLARATION

This thesis is my own work, conducted in accordance with the guidelines of the University of Edinburgh.



## ABSTRACT

Hospice care is believed to offer the best care for terminally ill patients (Manning, 1984). This thesis explores how patients on a hospice in-patient unit perceived and responded to surrounding dying and multiple deaths which they encountered. The approach to this ethnographic study incorporates the participant observation technique and underscores the symbolic interactionist component in generating a theoretical explanation. The theoretical explanation was guided by grounded theoretical analysis. A sensitising concept, 'openness to death', suggested in the literature on the hospice movement, provided direction for the fieldwork.

The fieldwork was undertaken over an eight month period. Patients admitted to the hospice in-patient unit during this time were potential participants. Selection of participants was based on their desire and consent, and/or their physical and mental capabilities to participate in the study. Assessments of patients' ability to participate were aided by information from attending hand-over reports and making regular rounds through the unit to check on their conditions. Staff and relatives' views are incorporated into the thesis.

This thesis explored whether patients' exposure to dying and death influenced their coming to terms with their own imminent death and whether this exposure reduced the death taboo. The data revealed three themes: 'concealing death', 'displaying dying' and 'responding to dying and multiple deaths and dying'. Some hospice patients must confront their imminent death, as well as the cumulative effects of room-mates' dying and their deaths, because they shared wards. This study questions whether this caused additional stress because of placement of patients in wards. Staff in the research site tried to minimise patients' encounters with dying and deaths, and attempted to neutralise their responses to these events, by various strategies such as transfers of some dying patients to single rooms. This was not always successful in wards because staff members could not manage the multiple deaths and dying. This thesis relates to Goffman's (1959) notion of 'performance' and how it can socially control people.

Hospice ideology is challenged through the strategies practised by the staff in this hospice. In this thesis the ways in which patients discovered death are discussed. Various elements of dying and death vigils are presented, and patients' and staff members' responses to dying and multiple deaths are explored.

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## CHAPTER 1

### INTRODUCTION TO THE STUDY

## Epitaph

... Empathy, if not absolute sympathy with the subject of one's study, provides the best method for understanding it.

First there is the story of a pious Muslim who had vast prejudices against the Hindus but had yet wanted to write a book about Hinduism. The pious man went to his Guru, himself a Muslim, seeking the latter's advice about his own desire to write on the life and religion of the Hindus. The Guru agreed to the proposal but imposed a condition on his disciple. It was that the writer would spend a year's time dressed as a Hindu and living all the rituals of the Hindu civilization to gain first-hand knowledge about his theme before he would settle down and write. The writer, after undergoing the test, wrote a piece which was very different from what he had originally intended to write.

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Dasgupta, S (1989) 'The core of Gandhi's social and economic thought' in *Gandhi's Significance for Today : The Elusive Legacy*, J Hick and L Hempel (eds), Basingstoke, Hampshire : Macmillan Houndmills, p:190-1

## The Objective of the Study

In this thesis, I present the results of an ethnographic study which focuses on the encounters of terminally ill patients with dying and multiple deaths in a hospice inpatient unit in Scotland.

My previous experiences as a nurse in Canadian hospitals, caring for dying patients on general units, as well as a longstanding personal interest in thanatology, influenced this study. None of my nursing experience, however, involved working within terminal care settings such as hospices or palliative care units. Hospice care is high profile within the domain of terminal care. That has been established by the flourishing development of hospices and palliative care units in Britain and elsewhere.

The topic of dying and deaths may seem morbid, however, it is a reality of life. Death is the outcome for most hospice patients. Death and dying are singled out as a topic for this study because they are important aspects of terminal illness that patients must contend with, over and above coming to terms with their own death. I wanted to explore patients' perceptions and the management of dying and death in a hospice setting.

The initial research problem was influenced by a body of research on terminal care in hospitals, palliative care units and hospices. A series of research questions were developed and progressively became more focused and defined during the fieldwork. The initial research question was pitched at a general level: what is going on in a hospice inpatient unit? During the fieldwork the research



questions were formulated more specifically: how are dying and death managed? How do patients feel and react to the dying and deaths they encounter and what are their views about them?

In order to answer these questions my presence on the unit and within the hospice environment, I believed, was necessary to form close relationships with patients and vice versa. This would enable me to understand the context of observations. In order to gather the necessary data I adopted the role of participant observer, although I did participate in some aspects of care and conversations with patients as they occurred. It enabled me to follow patients through the course of their admission until discharge or death. Eight months were spent undertaking the fieldwork. The fieldwork also included conversations and interviews. This ultimately offered a wider picture of the patients' perspective than could have been obtained by a single data collection exercise, such as a one-off interview or observation alone.

Since hospice care is held to offer the best possible care for the terminally ill, the appropriate location for this study was a hospice. Patients are the recipients of hospice care, therefore their point of view helps to understand the implications it has. Hospice philosophy integrates physical, psychological, social and spiritual care. In this study psychosocial care was explored. Physical care was a priority. Spiritual care did not play a prominent role in the fieldwork. Care in wards symbolises the hospice concept of sharing experiences. Because of these communal arrangements, patients witnessed their room-mates' experience of

dying and sometimes death. The advantages and disadvantages of communal care are discussed in this thesis.

Terminal, palliative and chronic care were offered to the patients in the study. Two types of patients, alert and comatose, were noted in the hospice. The alert patients were aware of events that occurred on the unit in a way that comatose patients were not. Although patients' perspectives are paramount to the thesis and the focus of it, relatives' views are also included. The importance of including relatives' views became obvious during the fieldwork. At the point when patients became comatose, relatives provided important supplementary information for the study. Input from the staff members is also included as part of the data as a means of corroborating patients' and relatives' views.

The objective of the study was not to test a predetermined hypothesis. The initial research question incorporated 'openness to death' as a sensitising concept which guided the study and was developed from the literature on hospice care. The sensitising concept is discussed in Chapter 4 of this thesis. It implied that the death taboo was eradicated in hospices. The sensitising concept related to how hospice care influenced the success of the hospice movement.

### **The Structure of the Thesis**

The thesis is divided into two parts. In the first part, in Chapters 1 to 4, I set out the basis of the study by reviewing existing research and by illustrating the development of hospice

care in relation to shortcomings of terminal care in other institutions. In the literature review, I examine research on care of the dying in hospitals as a basis for initiating the hospice movement. Communication in health care is examined in depth because of its significance to psychosocial care in hospices. Research on the hospice movement and the specific components of its care are discussed. Theoretical and practical issues of the research method used - participant observation - are presented in two chapters: in Chapter 3 issues of ethnographic research are discussed and Chapter 4 deals with the practical issues of participant observation, as it was developed in this study. Characteristics of the research site are incorporated into that chapter.

Presented in the second part of the thesis are the data which were obtained by participant observation. Patients', relatives' and staff members' encounters with dying and death on the inpatient unit were explored. The majority of data pertains to patients. Discussed in Chapter 5 are the issues of how death was managed on the unit and how patients became informed of deaths of their co-patients. The focus in Chapter 6 is on how dying was visible in wards and what patients witnessed. In Chapter 7 are the ways in which patients emotionally responded to the dying and multiple deaths they witnessed in wards and on the unit are presented. In Chapter 8, the three themes from Chapters 5, 6 and 7 are drawn together and discussed within the wider context of hospice care. Hospice ideology is compared with the practice I observed in the research site. Lastly, changes within hospice care are discussed, together with the implications of this thesis in relation to future

development of terminal care.

### An Illustration

The focus of this study is patients' experiences with dying and death in a hospice inpatient unit. The introduction to this study begins with a case illustration taken from the data. It introduces themes that are discussed in Chapters 5, 6 and 7.

#### Abbey : In the final acts

It is 3.20 p.m. and Abbey is in bed which is unusual for her. As we speak, several of the details she mentioned do not make sense and I wonder what is happening to her (0606:8).

Two days later, flipping through magazines on her bedside table, Abbey puts them away as I walk up to her. You were reading, I say:

A To pass the time. They put me to bed.

TM 'What do you mean? You've been in bed since three',  
when I arrived. With your 'nightie' on.

A 'Just keep your nightie on. It's better'.

TM 'For whom'?

A 'The nurses'.

Abbey asks me to give her some water. The glass is on the locker, to her immediate right and is out of her reach.

A 'Everybody that comes in I have to ask for a glass  
of water'.

TM 'Why'?

A 'Because nobody gives it without me asking'.

I offer more water which she accepts.

A 'I cannot keep pestering you'.

TM 'You're not'.

Abbey drinks again. I ask if her catheter is by-passing. Previously she explained catheter functioning and dysfunctioning and continues to do so:

A 'No. The more you drink, the cleaner it gets. Even at dinner time. On and on and on. Drink plenty of fluid'.

TM 'So drink more fluids, but they don't offer them?'

She shakes her head - no (6008:10-11).

#### Five days later

Five days later at 3.05 p.m. Abbey is motionless in the bed. I go up and speak to her while holding her hand, but she does not respond. Her partially open eyelids do not register whether or not she recognises me. I leave her ward and approach nurse Emma in the main corridor of the unit.

TM What's happened to Abbey?

E 'Diamorphine'. She was having 'back pain' and was switched from 'paracetamol to 1.25 of diamorphine'. She's been like that since.

TM Diamorphine does that or is it something other?

E She's been like that. I gave the first diamorphine.

TM Is she on her way out?

Emma nods her head in agreement and adds, I think so.

Anticipating Abbey's death before my next shift, I return to her bedside and clasp her hand. She squeezes mine and holds on, though her lifeless eyes betray that it may be nothing more than a reflex. Thanking her for her conversations with me, I struggle to leave; she clutches my hand and an ineffable emotion overwhelms me. I am losing a key informant and friend (0613:1, 6-7).

#### Two days later

Entering the ward two days later, auxiliary Doreen is seated beside Abbey's bed. That Abbey is alive is astonishing. Speaking with the patient Mrs Black in bed 2, next to Abbey's, auxiliary Sue joins us and I ask her about vacant beds 5 and 6. Mrs Black, another patient, pipes in, 'not Abbey'. No. 'Not Abbey' but she's ill, Sue responds. I'm thinking to myself Abbey is dying, as Sue holds Mrs Black's hand. Two auxiliaries enter the ward and go to Abbey's bed. They begin drawing her screens. I join them. Nancy, another auxiliary, speaks into Abbey's left ear that they are planning to turn her. They proceed with the turning. Returning to Mrs Black's bedside, we talk about the recent deaths and I ask 'what about Abbey'? Abbey is now on her left side, softly Cheyne-Stoking (a characteristic breathing pattern that precedes death).

Patient in the bed beside Abbey

B     'All the time my thoughts are with her ... I feel  
for other people'.

'How about yourself'? I ask. Mrs Black lifts her left hand upward, palm open, as her eyelids widen. Her eyes and hands seem to ask, does it matter or make any difference, what can I do. Though we do not exchange words, her gesture seems to reflect calm resignation and powerlessness.

TM    'How do you find passing time since you've been in  
bed'?

B     'Terrible, terrible, terrible'.

TM    'Are you giving up'?

Without voice, her lips form the word 'no'. Simultaneously she shakes her head 'no'.

At 4.20 auxiliary Denise enters the ward. She removes the chair Emma sat on beside Abbey's bed. Tidy up and keep the ward neat, I muse. Momentarily Sister Nora enters the ward and goes to Abbey. She bends forward and looks as though she is speaking to Abbey, but I cannot hear her words because I am with patient Elsa. Nora leaves, then returns with Kevin, Abbey's son. Nora walks to the conservatory and returns carrying a chair, like the one which Denise removed minutes ago. Two auxiliaries enter the ward and one joins Mrs Black in her cubicle.

I have been in the ward for 45 minutes and the staff are meandering about. It is a slower period in their shift now, as it is visiting hours. Is this reactivity I wonder? Or is the increased attention and surveillance in the ward to monitor Abbey and Kevin and to be present at the time of Abbey's death.

I overhear auxiliary Marilyn saying to Mrs Black, 'Aye, she died. Aye. Aye Naomi, biblical name ... All her family had biblical names ...' Jenny, another auxiliary enters the ward and joins the conversation about Naomi, who died this morning after a two month admission.

Kevin is sitting beside his mother's bed. He is making sniffing noises, sobbing, not crying; no tears nor tissues.

Marilyn looks at me for several seconds as Jenny reads from a tabloid on the overbed table and says to Marilyn:

J    'Are you going on holiday'?

M    'I quite fancy going to Jersey'.

Kevin is alone and, suspecting that he may remain until his mother dies, I ask him if he would like to go for coffee. He accepts the offer and we leave the ward.

Following the coffee break we part as Kevin leaves the hospice for home. I return to the unit. It is 5.25 p.m. and the staff are serving tea, while Abbey is alone (0615:1-4, 7). From the conservatory, at six o'clock, I notice that Abbey's cubicle screens



are closed. Suspicions aroused, I enter the ward and slip behind the screens.

Abbey is on her back, with her dentures now in place. A towel circles and supports her neck. Her face is relaxed now. Not pinched as it was in dying. Her silently still body lies upon the bed, which is concealed from public view by the screens.

Death is the end, so to speak. However, in this context it is not. Abbey was a key informant who conversed with me in her insightful, humourous, oft emotive and animated way. Together we acquired a system for working, through trial and tribulation. Hesitatingly she spoke, pausing often, except when stirred by emotion. Her pauses enabled me to write in my journal (0615:8-17).

This case study and others like it will be drawn on in discussion in the ensuing data chapters.

## CHAPTER 2

### LITERATURE REVIEW

## Introduction

Many empirical studies and publicity in the mass media have sparked society's curiosity and exposure to the mysterious events of dying and death. For the past three decades researchers have been studying the process of dying in hospitals and more recently in hospices with a view to improving institutional care for terminally ill patients. As the veil of secrecy towards dying was lifted, now relieved of the burden of silence, and with proliferated media attention devoted to death, the word became 'fashionable' (Paula, 1967).

During this period, the present day hospice movement began in Britain and has expanded internationally. Cicely Saunders, a British physician with experience in several disciplines such as social work and nursing, founded the present day hospice movement. Her affiliation with hospice care began in the 1950s at St Joseph's Hospice in London. She established St Christopher's in a London suburb in 1967 to care for the terminally ill because, as du Boulay (1984) acknowledged, Saunders was discouraged by the management of dying patients in hospitals. Hospices developed because of the unsuitable, depersonalised and fragmented care in hospitals (Wilkes, 1981; Paradis, 1985; Lynn, 1985). The hospice movement proclaims and promotes humane care for the dying. Quality of life is the aim of hospice care (Saunders et al 1981). Hospices assemble terminally ill patients in dedicated facilities and provide services to meet their specific needs. Central to the hospice philosophy is thanatology and care which palliates and removes the symptoms of terminal illness. Psychosocial care is

provided to patients and their relatives.

This chapter reviews British, North American and European research and literature on death and dying and terminal care in general and especially in hospices. The chapter is composed of three main sections. The first briefly introduces societal attitudes to dying and death. Studies on hospital care of the dying are interspersed with pertinent research on hospices to form the second section. The last part focuses on hospice care specifically.

### **Attitudes Towards Dying and Death**

This section examines attitudes towards dying and death. It includes comments that are made about people's fears of dying. Mortality is discussed from an existentialist perspective through to the institutional management of death and dying. Human mortality was identified by Weber (1947) as of great sociological importance because of the way human action is oriented to it.

Existentialism identified anxiety toward death as ever present in human beings although their attitudes and anxiety to it vary. People's awareness of their mortality is ever present. Existentialism is directed toward mortality, the uncertainty of it and the anxiety it can arouse (MacQuarrie, 1972). The uncertainties humans face in meeting death are referred to by existentialist philosophers as the 'anxiety of nothingness' (May, 1975). Anguish is a common theme in existentialism (Warnock, 1970). It recognised the flux between 'a sense of dread, terror and revulsion' and a 'sense of exhilaration and sublimity'. The

existentialists recognised the anxiety and anguish to death in its many forms within the empirical world. MacQuarrie identified society's attitude towards death as one of avoidance which was facilitated because death is hidden.

It is of course, natural to fear death or to be anxious in the face of death. But this is very different from constructing a vast cultural illusion (to say nothing of a highly profitable industry) to help us forget about death or to persuade ourselves that it is unreal (1972:198).

Through the institutionalisation of dying and the funeral industry's management of death, death is camouflaged. Martin (1975) argued that corpses are staged to portray sleep. Hospice nurses' work can be compared to funeral directors' work. Martin cited Kierkegaard (1973) who described existentialism as pertaining to the individual's death. Thus death anxiety referred to the individual's own death rather than death in the collective sense. This issue is relevant to terminal caregivers and their expectations of the type of care they provide and their responses to death. Their own attitudes and feelings influence their work and could impede the emotional care that they provide.

Advancements in medical science have increased people's life spans. Historically death was visible in society when it frequently occurred at home. Glaser and Strauss (1967) and other researchers (Fulton, 1965; Sudnow, 1967) argued that as illness and dying became institutionalised, society had less contact with dying and death. Death became taboo when it was institutionalised (Fulton, 1965). Millett (1979) identified American society as a 'death-denying culture' where medicalised dying removed death from

society. Benoliel (1970) examined care of the dying in hospitals and asserted that death was specialised, depersonalised and fragmented in American hospitals.

Kastenbaum and Aisenberg (1972) identified three death fears people experience: the fear of the process of dying, the fear of being dead and the fear of extinction. In another study of patients dying in hospital, their concerns were more pragmatic. Hinton (1967) found that patients feared how long it would take, whether physical suffering would be present and whether it would be relieved if it did occur.

### **Institutional Practices in Care of the Dying**

In this section I discuss how terminal care was managed in hospitals and how deficiencies in those services influenced the evolution of hospice care. Topics included are isolation of dying patients and communication practices. Traditional terminal care in hospitals abandoned care when cure was no longer possible and inappropriately relied on technological intervention with dying patients (Davidson, 1979). Charles-Edwards (1983) acknowledged that hospitals pushed for active treatment despite terminal prognoses suggesting imminent death.

#### **Isolation of dying patients**

Isolating practices used with patients dying in hospitals are now discussed. Isolating dying patients reflects the need for privacy of dying people. Dying patients encountered two types of isolation

in hospitals, social and physical. Charles-Edwards (1983), Glaser and Strauss (1965, 1968), Quint (1967) and Sudnow (1967) argued that the isolation imposed on terminally ill patients resulted from the discomfort hospital caregivers experienced working with patients close to death.

Sudnow's ethnography of 'the social organization of dying' in two hospitals, revealed that nurses' interactions with terminal patients varied according to their expectations about the certainty and time of their deaths. He and Glaser and Strauss (1965, 1969) found that 'social death' occurred before patients' biological death. Nurses treated patients as though they were dead once they became comatose. Sudnow identified how hospitals developed routines to deal with the dying. Social isolation of these patients commenced when nurses avoided patients once prognoses were disclosed (Glaser & Strauss, 1964, 1965). Fulton (1976) argued that dying patients were forced into 'psychological isolation' by the process of dying itself and its management. He noted that patients were psychologically isolated by their prognoses and the way that they were cared for. Glaser and Strauss (1964, 1965, 1968, 1977) and Sudnow indicated the tactics that some caregivers used to socially isolate the patients. Several other studies identified that dying patients were shunned by caregivers who were uncomfortable working with them (Quint, 1967; Field, 1989; May, 1991). Nurses used superficial conversations with patients (Quint, 1967). Field found that through tasks, nurses were able to evade patients' questions. May's interview study of nurses on two wards in a general hospital found it task-oriented and, when patients were in side rooms, it helped the nurses. Placing dying patients

in side rooms enabled the nurses to avoid these patients.

One isolating strategy used is physical isolation. Bond and Bond (1980) noted that single rooms in hospitals were often allocated to dying patients. This strategy, Charles-Edwards (1983) asserted, enabled caregivers to evade patients and their questions about their conditions:

There are all manner of justifications for this: less noise, less bustle, more privacy and so forth. However, it can also be a very satisfactory means of reducing to a minimum everyone's discomfort concerning the dying patients (1983:2).

Physical isolation was justified as the basis for privacy. Similarly, May (1991), who interviewed hospital nurses working with terminally ill patients on acute wards, found that single rooms offered 'concrete privacy'. That privacy benefited the patients, their relatives and the nurses. The seclusion enabled the nurses to attend to other tasks and evade the patients. Thus privacy was used to the nurses' advantage to meet competing work demands.

On an acute surgical ward with the majority of admissions for cancer, the layout of the ward allowed heavily sedated and terminal patients to be segregated from the other wards, either in a 6-bed bay or in 3 single rooms (Knight & Field, 1981). Problems could have been experienced in the bay where patients witnessed each other's dying.

Thoreen (1983) advised against segregating dying patients in private rooms. He advocated ward care, where 'roommates' may be a



source of support and comfort' (p:261), in his examination of terminal care in long-term care facilities. Collective care is one of the tenets of hospice philosophy. The practice of isolating dying patients is a controversial issue in terminal care. It occurs in hospitals, whereas hospices have allegedly banished the practice although side rooms are still available in them. Their usage is discussed throughout this thesis.

Terminally ill patients can experience social and physical isolation, where dying is hidden and justified for several reasons.

#### Communication practices

Literature on communication and nurses' relationships with patients are presented in this section because of their role in nursing in general and the development of hospice care in particular. Much of the literature is taken from hospital situations because hospice psychosocial care developed in response to problems experienced in acute care situations. Studies undertaken in the past three decades from sociological, psychiatric and nursing perspectives related to communication in health care, are drawn on. These studies reveal how communication facilitates or hinders nursing care. Field (1989) argued that nurses view relationships with patients as an important part of their nursing care and this is a generally accepted tenet of nursing. Hospice principles partially developed in response to what was perceived as unsatisfactory communication with dying patients in hospitals.

Studies conducted by sociologists, psychiatrists, nurses and doctors in the early 1960s supplied evidence for the view that dying patients benefited by discussing their experiences (Feifel, 1963). In 1961 Weisman and Hackett studied the pre-death responses of five terminal patients. They found that the patients were not 'anguished or depressed' with the closeness of their death. Other researchers have made similar observations that patients benefited by talking about these events (Eissler, 1955; Hinton, 1967; Kubler-Ross, 1969; Qvarnstrom, 1978). Eissler's work preceded that of Kubler-Ross. Eissler, a psychiatrist, spoke to dying patients about their feelings towards dying which assisted them through their experiences in hospital. Hinton studied patients dying in hospitals and worked through their feelings and experiences of the way they die and their care. Qvarnstrom noted that conversations with patients about their dying were difficult for nurses and that they required support with this type of work. Quint (1967) and Sudnow (1967) stressed that nurses develop interpersonal relationships with patients which met therapeutic objectives. Weisman and Hackett and Kubler-Ross studied hospital patients and did not consider the influences of collective care which are issues in this study.

Glaser and Strauss' 1965 study began with an interest in how nursing and medical care was provided to the terminally ill on several hospital cancer wards. They found that physical care and technical skills were the focus of the ward work. Through participant observation they studied interactions between the staff and patients and examined patients' knowledge about their prognoses. They discovered the process by which the patients

realised they were dying, this being embedded in the disclosure of information to them. They described patients identifying their prognoses simultaneously with responses from nurses and others. Glaser and Strauss noted how communication was disclosed or controlled about patients' prognoses. Patients' awareness of their terminal conditions depended on what type of information was given to them. These researchers developed the notion of 'awareness contexts' which pertained to the different levels of information about conditions made known to patients. Awareness contexts, Strauss (1987) asserted, reflect control of information and are common in health care relationships. In the 'closed awareness' context the staff withheld information from patients about their diagnoses and prognoses. 'Suspicion awareness' operated when patients suspected, but were not given, knowledge about their condition. With 'mutual pretence awareness' information was known to caregivers and patients although both parties carried on as though the prognosis was non-existent. With 'open awareness' the information about the prognoses was shared by everyone.

Glaser and Strauss pointed out doctors' and nurses' apparent reluctance to speak openly about death and dying with patients who were close to death. Previously, the fear of distressing patients had prevented investigators from broaching the subject in a frank manner (Hinton, 1967). Hinton (1967) and Kubler-Ross (1969) both discovered caregivers' unwillingness to deal openly with death. They attributed it to caregivers own fears. Kubler-Ross (1969, 1975), a psychiatrist, emphasised the advantages of communicating with dying patients, this enabled them to address their concerns. She interviewed patients and described how they managed their

situations and identified five stages they experienced: denial, anger, bargaining, depression and acceptance. Through Kubler-Ross' work, talk about dying became more acceptable. She noted patients' reactions to their prognoses and the advantages of communication so that they could confront, and hopefully accept, their imminent death. Gradually work with the dying was viewed as rich in challenges and rewards. However, Qvarnstrom (1978) and Parkes (1979) are sceptical that patients progress consecutively through the stages which Kubler-Ross outlined and indeed Kubler-Ross herself has acknowledged this (Saunders & Baines, 1989). Kubler-Ross now argues that the progression may not be as clear cut as she had suggested and some stages may not occur at all.

Communication in acute care settings shows similar features. Qvarnstrom (1978) interviewed 15 patients, most of whom had cancer, staff members and relatives on a medical ward in a general hospital. She found that listening to patients was not considered by nurses to be work. Like Kubler-Ross, Qvarnstrom found that when patients were enabled to discuss their concerns they benefited. Five patients dying in an acute hospital were interviewed by Paige (1980) and she suggested that they derived a psychotherapeutic benefit by communicating their attitudes towards death. The following studies reveal problems in achieving these conversations.

Macleod Clark (1981) studied communication interactions between nurses and surgical patients by using a radio microphone and audio and video recordings, as well as observations. Hers was one of the most comprehensive such studies. Interactions averaged 1.7 minutes: 2 minutes for students and 1.3 minutes for staff nurses.

These figures are, however, distorted by occasional lengthy conversations. Macleod Clark focused on the failure of nurses to attend to patients' psychosocial needs. However, they were not given the opportunity to explain why they used the observed conversational tactics during encounters with patients. Faulkner (1980) and Bond (1978) noted evidence of tactics similar to those found by Macleod Clark. Faulkner monitored student nurses' conversations with a radio microphone attached to the nurses. Their conversations lasted 2-3 minutes per interaction on average. Students appeared to converse with patients longer than staff nurses. Bond found that nurses limited cancer patients' attempts at discussing psychosocial issues. She noted that nurses in a radiotherapy department engaged patients in brief social conversations while they undertook their work. They said they did not consider patients' personal problems to be their responsibility. Verbal interactions lasted approximately 3 minutes on average, unless the tasks being performed were longer. The duration of verbal interaction was generally short and little of the nurses' total time was devoted to this aspect of patient care.

Student nurses' difficulties with communication and working with dying patients have been shown to pose problems for them. Birch (1979) found that nursing the dying and talking to their relatives was reported to be the most stressful aspect of students' training. It related to their lack of supervision in this area. Quint (1967) studied students' interactions with nurses and mastectomy patients. She found that nurses avoided conversational difficulties with patients by directing the discussion to safe topics. They focused their attention on the procedures being done. Student nurses were

found to distract patients from difficult topics through superficial conversations. The students learned from experienced nurses to curtail their involvement with patients because the encounters were emotionally difficult for them. Whitfield (1979) presented a questionnaire to student nurses about their experiences with dying patients. She found that patients' psychosocial needs were not discussed by the staff nurses, according to the students. The students believed this impeded them from providing supportive care in meeting patients' psychological and spiritual needs. Melia (1987) in her study of student nurses' training found that they believed sitting and talking to patients was not 'work'. They evaded patients' questions about their conditions because their information about patients' conditions was limited, they were uncertain about what patients knew of it and were told by superiors not to disclose information to patients.

Chapman (1983) singled out communication as a priority of care but noted that nurses' conversations were often superficial and impeded patients from discussing their concerns. Patients did not want to bother nurses with their concerns in Stockwell's (1972) study of interactions on a geriatric ward, because they believed the nurses were too busy to talk to them. She observed that verbal interaction between nurses and patients was infrequent and short. Most interactions were task-oriented and superficial and some tasks occurred without verbal exchanges. The 'unpopular patient' was given less time by nurses to communicate because they were demanding of nurses' time and were perceived to be unappreciative of what was done for them. Patients were reticent to discuss their fears related to information about their illness, in McIntosh's



(1977) study on a cancer ward, unless given opportunities by the staff.

Cartwright et al (1973) identified the 'conspiracy of silence' that existed between health care workers and relatives to withhold information from patients about their terminal prognoses. The researchers studied the care and needs of 960 people during their last year of life, from recollections of their caregivers. They found that communication and co-ordination between agencies that cared for the patients was sometimes open and other times not.

Nursing care of patients dying in a medical ward was studied during their last week of life by Mills (1983). Through her observational study she found that the care was routine-oriented, directed by the physicians and that nurses' interactions with patients were brief. This point is supported by Thompson et al (1983) who argued that nursing care is a set of routines and that individual patient's needs were relegated to the routines. Whitfield (1979) identified in her study of student nurses that care focused on the physical care and the psychosocial care was deficient. Knight and Field (1981) studied an acute surgical ward which cared for cancer patients. They were thought to suggest that encounters were routinised and organised around the tasks and argued that this was part of the management of communication between nurses and patients. They were thought to have argued that failure to disclose prognoses was thought to protect patients from depression and anxiety, that the ward routine could become disrupted by the disclosure of death. Faulkner (1980) also identified superficial, routinised, task-oriented care. Quint (1967) and Stockwell (1972) argued that

nurses control encounters with patients. Quint has suggested that superficial conversations were part of a deliberate strategy to distract patients from their concerns while focusing on tasks, as did Bond (1978). Bond noted that when patients attempted to focus on psychosocial issues of their illness, nurses engaged in tactics to minimise this. She argued that nurses organise communication so as to restrict the information they receive from patients. The nurses in her study defended this strategy as allowing the possibility of hope for patients against the uncertainty of their illness. This strategy points to a moral dilemma.

Although nurses encounter death and dying in their work, Chapman (1985) argued that nurses perpetuate the death taboo, as do medical staff, through behaviour such as engaging in superficial conversations with dying patients when cure is impossible. However, Gow's (1982) study of nurses suggested a reason for this behaviour. Some nurses reported that their own fear of death thwarted communicating with patients about it. This is the view put forward by existentialists. Field (1989) studied nurses working on an acute surgical ward, general medical ward and coronary care unit and in the former found that nurses received no support or encouragement to talk with dying patients. Thus patients were lonely and anxious. Millett (1979) argued that hospital care subordinated patients' psychological needs to physical care because of time constraints and the difficulty of tackling these issues.

Thompson (1979) argued that communication between nurses and dying patients would improve if nurses were better educated about death



and dying, were better informed about the patient and their family circumstances and if emotional support was given them by their colleagues. This recommendation is claimed to be part of hospice philosophy and is discussed later in the thesis.

Although the benefits of open communication were noted earlier in the section, the majority of studies identified deficiencies in communicating with the terminally ill. Although nurses wish to devote time to meeting psychosocial care for patients, there is little evidence to suggest that this occurs (Hockey, 1976). Patients apparently do not discuss their concerns because they perceive nurses as too busy to talk, which prevents them from attending to more seriously ill patients (Macleod Clark, 1982; Stockwell, 1972). Hospice care was developed to confront communication problems with dying patients, as well as other aspects of their care which will be discussed later in the chapter.

### **The Genesis and Fundamental Elements of Hospices**

Modern hospice care has its roots in hospices operating during medieval times when they provided lodging and spiritual knowledge for travelling pilgrims (Halthon, 1986). Hospices are recorded as operating as early as the fourth century. Paradis (1985) points out that these early hospices were located throughout Europe and run by religious orders. Thus the link to spiritual care in modern hospices.

Hospice care emphasises holistic care for individuals. Holistic care integrates physical, social, emotional and spiritual

dimensions. Saunders et al (1981) point out that quality of life in peaceful centres is striven for. The high staff to patient ratio in hospices are being questioned as to their claims (Gray, 1977; James, 1986; Field, 1989). The high staff ratio is believed to contribute to the excellence of patient care in hospices. Saunders' (1986) work underscores the role of research and education in hospices to improve terminal care.

Hospices have been developed because traditional health care for the terminally ill provided fragmented care (Lynn, 1985). Care of the terminally ill in hospitals focused on curative aspects and attention to pain control. Wilkes (1981) attributed the growth of the hospice concept to the unsuitability of traditional terminal care. Hospice care has spread throughout the world and developed in various forms according to Abel (1986). Free-standing hospices, independent and voluntary, which are prevalent in the UK, manage all levels of care and isolate terminal patients within these facilities. Other hospice models are NHS units which are attached to or integrated within hospitals. Palliative care units or continuing care units that are attached to hospitals utilise their resources, such as radiation therapy (Davidson, 1979).

The nature of hospice care has changed over the centuries and currently focuses on different types of terminal illness, as well as chronic conditions. Almost 70 per cent of deaths in the UK take place in hospitals and other institutions (Field, 1989).

### Contemporary hospice care

Hospice care is described as being many things. Thoreen (1983) identified hospice care as a 'philosophy' of care, a 'program' of care, or a 'place' where care is given (p:246). Goddard (1990) defines it as 'hospice care represents a way of caring, or philosophy and set of attitudes which can be disseminated into both the hospital and community sectors' (p:11).

When cure is impossible the hospice approach, Corr and Corr (1983) maintained, is an option for people with terminal and chronic illnesses. Cicely Saunders emphasised pain control, palliative care and psychosocial support for patients and their relatives as key factors in hospice care (du Boulay, 1984). Manning (1984) outlined hospice care as meeting patients' total needs as does Doyle (1984), who adds that such holistic care requires 'team care'. Hospice staff members work as an interdisciplinary team because, as Parkes (1979) maintained, one discipline cannot respond to the many and varied needs of dying patients and their relatives. 'Total care' in hospices, Doyle asserted, encompasses 'team care' in meeting patients' 'physical, emotional, social and spiritual' needs.

Hospice philosophy is based on a model which encompasses the inclusion of the patient and their family in the care, research and education (Saunders, 1980). Discovering and advancing therapy is an objective of hospice care. Thus research and education are vital to improving terminal care (Saunders, 1986). Fifty per cent of hospices or palliative care units in the UK offer educational

programmes for nurses and doctors (Doyle, 1985).

Hospices have attracted society's attention and attitudes to dying and death (Butler, 1979). Hospice philosophy views death as a natural dimension of the life cycle (Halthon, 1986; Millett, 1979; Saunders, 1967). Paradis (1985) argued that the hospice movement has generated fundamental social changes in attitudes towards death. Hospices responded to what she calls 'a social problem: the depersonalisation of care for the terminally ill'. Doyle (1984) acknowledged the societal fear of death and believed it is the role of terminal caregivers to assist patients through their experiences with death. By 'openly communicating feelings and beliefs' about death, hospices enable wider social acceptance of death, Cotter (1981) believed. Millett (1979) argued that hospices 'humanise the process of dying'. Davidson (1979) believed they provide appropriate and adequate terminal care.

#### Hospice expansion

The hospice concept has spread throughout the world in various forms since the opening of St Christopher's Hospice in London (Abel, 1986). Now nearly a quarter of a century since the founding of St Christopher's Hospice, 113 independent hospice inpatient units exist in Britain (St Christopher's Hospice Information Service, 1992). Seven independent hospice inpatient units, with more planned to open, two NHS units attached to hospitals and one AIDS hospice are currently operational in Scotland (St Christopher's Hospice Information Service, 1992). The expansion of independent hospices has occurred despite recommendations advising

against it. The rapid expansion in hospice services led to the British Standing Medical Advisory Committee in 1980 recommending restricting the growth of free-standing inpatient units and suggested integrating hospice and hospital services. They recommended combining hospice care within hospital services. Their recommendation foresaw limited funding and the problem of attracting trained staff for these specialised units. The committee suggested a comprehensive evaluation of hospice services. To date that has not occurred. Expansion of hospice units continues, although many hospices are partially funded by the NHS (25% of funding).

Care for the terminally ill is also provided through other hospice-type 'agencies' such as: Macmillan Cancer Care Units, Marie Curie Cancer Centres and through the Sue Ryder Foundation (St Christopher's Hospice Information Service, 1992).

The hospice movement offers bereavement counselling services to relatives (Paradis, 1985). Bereavement services that were offered to relatives may extend beyond a year after patients' deaths (Millett, 1979). In this context Barazelais' (1981) statement that hospices benefit relatives more than patients is relevant. Respite care is another feature of hospice care. It allows relatives a break from caring for patients at home. Kindlen (1987) studied hospice home care services from the perspective of various types of nurses and found that the peaceful hospice atmosphere is more appropriate for dying patients than hospitals because hospices offered respite care.

### Pain management

Saunders's (1965) attention to cancer pain led to pharmacological research that advanced the management of pain in terminal care. Her priority in hospice care was managing all symptoms, especially pain. She asserted that physical pain must be kept in remission, which Doyle (1984) emphasised should be managed by routinely administering medications rather than waiting for pain symptoms to appear. Management of pain, especially for patients with cancer, was haphazard in hospitals according to Milette (1979). Analgesics were often administered after symptoms appeared. Twycross (1974) encouraged using heroin derivatives for the pain experienced in advanced malignancies as the majority of disease conditions suffered by patients in hospices were carcinomata. Drugs are the first choice of therapy in cancer pain management. Other approaches to pain management include palliative radiotherapy, nerve blocks, physiotherapy and diversional therapies.

Saunders (1967) developed the concept of 'total pain' to describe the physical, emotional, social and spiritual elements of pain. She suggested that unless these elements were confronted, pain relief would remain challenging. Campbell (1986) suggested the primary focus of hospice care is 'total pain' control.

The hospice movement's contribution to physical pain management and symptom control for the terminally ill is well documented. Pain management lends itself to monitoring and is recognised in hospice studies (Kilroy, 1981; Wright, 1981; James, 1986; Hockey, 1986). Yet, 66 per cent of patients with advanced cancer will experience

severe pain (Arkinstall, 1987). Twycross and Lack (1983) found that 25-30 per cent of cancer patients do suffer little or no pain. Studies vary in how many patients suffer pain. In James' (1986) participant observation study on a continuing care unit, patients whose pain was problematic to manage were sedated into unconsciousness.

Ten to twelve years after St Christopher's Hospice opened in London, Murray Parkes (1984) studied patients' pain management in hospitals and in that particular hospice and he noted no significant differences in pain management. An emphasis on pain management is, however, no longer exclusive to hospices (James, 1986). Parkes and Parkes (1984) suggested that this may be the result of the influence of hospice education on hospital practice and the educational services offered by hospices to medical practitioners. Kane et al (1984) drew a similar conclusion about the similarities of pain management between hospice and hospital care in an American study. Macdonald and Macdonald (1992) sent postal questionnaires to 342 doctors before and after a hospice opened in Ayrshire. Following the opening of the hospice - one year later - the hospice seemed to have had a favourable influence on aspects of pain management in hospitals.

#### Individual, psychosocial care

The individual patient and their holistic needs are the basis of hospice care. Patients' concerns are paramount to hospices (Davidson, 1979; Frelick, 1980; Halthon, 1986). Paradis (1985) and Mor (1986) singled out the hospice's attention to providing



psychosocial care. How this care is provided and what it achieves is controversial. Lack (1977) contended that too much attention to emotional needs and too little to basic care was apparent in hospices. She used as an example the inappropriateness of providing supportive care to patients in wet beds. If basic care was provided she believed that patients and others could then meet patients' emotional needs.

Patients' participation in their care is another element of psychosocial care. Saunders (1978) encouraged hospice patients' participation in their care. This principle is, however, problematic. James (1986) studied nursing care on a continuing care unit by participating as a nurse to determine whether hospice ideals were implemented in practice. She found that enabling patients to participate in their care entailed admitting patients capable of such achievement. During her study elderly, docile patients were admitted who were uninterested in participating in their care. These patients frustrated the staff who strove to maintain the participative hospice ideology. The hospice administration instituted a change in policy which admitted younger patients and that remedied the situation. Younger patients desired to participate in their care. James pointed out that physical care was priority over psychosocial care. James' participation as a nurse detracted from her role as a researcher because she could not stand back and survey the care. Also, the physical exhaustion from her nursing role influenced whether field notes were tape-recorded or written. These are disadvantages of participatory roles. Because James restricted her study to nurses, she limited determining whether patients believed ideal hospice care was being



delivered. Admission criteria in Hockey's (1986) study of a hospice, nursing home and support organisation, revealed that patients close to death were prevented from being admitted into the hospice. Also, only patients who were aware of their prognoses were admitted to this hospice. It appeared that patient selectivity was a factor in maintaining hospice ideology because the care was compromised without it.

Individual psychosocial care in Munley's (1981) comprehensive, but unfocused, American participant observation study of hospice care, written from a theological perspective, found that the hospice social structure enabled 'individuality' and 'intimacy' in a supportive environment for patients and relatives. Munley interviewed 118 people, of which only 15 were patients. She argued that more patients were not interviewed because physically they could not withstand intensive interviews. Her participants believed that pain control and 'spiritual and emotional' support were superior to that provided in nursing homes and hospitals where they had previously been admitted. Munley's study resulted in a handbook approach to all aspects of hospice care. McDonnell (1987) studied several hospice patients' perceptions of their care by two unstructured interviews. The first interview occurred pre-admission to the hospice and the second eight days post-admission. During the first interview some of her respondents were unaware they were being admitted to a hospice, but she found patients praised the care they received. She concluded that the patients were satisfied with their care. It is questionable whether her findings are valid. It would be interesting to discover patients' responses if they were informed about being admitted to a hospice,

which might have captured their preconceptions about a hospice. Also, the closeness of patients' interviews may have affected respondents' perception of the care.

Hospice staff members' willingness to engage in discussions with patients about their dying is a cornerstone of hospice philosophy. Glaser and Strauss (1968) viewed the psychosocial care hospices provided as gauging patients' readiness to discuss their dying and gained their trust by openly confronting the issues. Stedeford (1981) found that on a continuing care unit, patients were satisfied with the communication between them and their relatives because the staff made time to listen to them.

Two studies conflict in their findings about whether hospice patients' awareness of their prognoses differ from hospitals. Hinton (1979) compared hospice patients with others in different settings and found hospice patients were more aware and spoke about their prognoses more often. Parkes (1979, 1984) studied St Christopher's Hospice patients' awareness of their diagnoses and prognoses at two year intervals, ten years apart, and found they were not more aware than hospital patients. Over half the hospice patients were unaware of other patients' deaths in their wards (Parkes, 1979). In McDonnell's (1987) study some patients were aware of deaths and upset by them. They may then have realised that they were admitted into a hospice. Yet, Butler (1979) held discussions with hospice workers who discussed their conscious efforts not to become too involved with dying patients. He suggested that psychological care could be expanded in that setting, although adequate physical care was provided. In another

study Wilson (1985) found that caring for patients' emotional needs was considered by hospice nurses to be more stressful than physical care. Patients' emotional needs placed considerable demands on the staff. Again, like with nursing in general hospitals, the emphasis on physical care was noted. Similarly with Gray's (1977) study which emphasised nursing care of hospice patients. She noted that despite nurses' awareness of patients' individual psychosocial needs, their work focused on physical care. She observed that hospice nurses spoke about valuing the individual patients but, more specifically, mentioned the problems that may arise because of patients' individuality. Although nurses in her study recognised the importance of patients' individuality, it did not lead to the definition of problems connected with the individual needs of specific patients. Field (1989) noted that task-oriented care resulted in the evasion of patients' questions in hospitals. James (1986) made a similar observation on a continuing care unit, where, because of 'resource constraints', the emphasis shifted from psychosocial care to physical care.

The provision of psychosocial care in hospices which is believed to distinguish hospice care from hospital care of the terminally ill, appears to differ between hospices.

#### The impact of dying and death

The impact of dying and death in hospices affects both patients and staff members. McPhee et al (1979) recognised patients' potential distress on being admitted to hospice units because of the dying that occurred within them and that frequent deaths may affect

patients and staff working in that environment.

A criticism levelled at hospices, Millett (1979) noted, is that congregating terminally ill patients in separate facilities isolated them from the living. She argued that the hospice is not a 'death house'. The belief that hospices are places for death has been dispelled by hospice proponents according to McArdle (1985). Publicity from hospice representatives promoting hospice services, fund-raising campaigns such as sporting events and telethons, charity shops, donation containers in shops, have kept hospices within the public profile, but have not necessarily dispelled the view of them as 'death houses'. In McDonnell's (1987) hospice study, she noted that patients were bothered by the presence of dying patients in wards. In another hospice study, Lugton (1986) noted that some patients and relatives were upset with the dying and death they witnessed. Wright (1981) argued that the frequency of deaths in hospices were a rehearsal for patients' deaths, without consideration to their effects. He recognised the advantages but not the disadvantages and the detrimental effects to patients' well-being.

Thoreen (1983) identified that staff members should inform patients, when appropriate, and if they asked, that another patient was dying. He believed that silence about dying was inappropriate in organisations where people died. The delicate interplay between providing support to dying patients and caregivers receiving support is essential to terminal care. Nurses that encounter pain, illness and dying require support. Pannier's (1980) participant observation study explored hospice caregivers' views to determine

their motivation to work with the terminally ill and its meaning to them. She identified three groups of caregivers: the 'social reformers, experiencers and disciples'. 'Social reformers' came to hospices to change care for the terminally ill. 'Experiencers' came to experience working with the terminally ill. The 'disciples' had a religious mission for these patients. Wilson (1985) argued that hospice nurses were no more susceptible to stress than nurses working in other specialities. It will be shown later in this thesis that other researchers disagree with this finding. Saunders and Baines (1989) recognised the bereavements that hospice staff must confront and they advised that support from the hospice administration was necessary. In Wright's (1981) brief participant observation study in a hospice, he found routinisation of 'dirty' work related to the tasks of caring for corpses. Though the staff in his study recognised that traditional routines depersonalised care, he argued they were necessary for staff to cope with the work.

McArdle (1985) pointed out the importance of training hospice staff for their encounters with dying patients and death and that not all were proficient, to the same degree, in clinical and psychosocial skills. Nurses' contact with dying and death is stressful as Charles-Edwards (1985) argued about hospital nurses and other researchers (Gow, 1982; Vachon, 1987) noted about terminal care. McArdle argued that hospice management must recognise the stressors because of frequent encounters with death. Corr and Corr (1983) examined hospice care, Bond (1978) explored terminal care in acute situations and Vachon (1986) studied palliative care and all concluded that support within the nursing hierarchy was necessary

for sustained work with dying patients. Grief is an emotion that caregivers are susceptible to and which should be addressed through regular group meetings, according to Parkes (1986). Thoreen (1983) advocated regular support groups, for those working with dying patients, buddying staff and the availability of a psychiatrist or social worker as required.

Munley (1983) recommended the necessity of incorporating hospice principles into main-stream health care. Abel (1986), James (1986) and Seale (1989) question whether hospice ideals are maintained in practice. In Seale's review of hospices he argued that terminal care in hospices was not uniquely different from hospitals.

Wright (1981), in his participant observation study in one hospice, argued that hospices engage in routines to deflect the dying and deaths they encountered. Macleod Clark (1983) viewed the control and limits nurses who engaged in their communication with patients as a protective function against the stress and anxiety they experienced in their hospital work.

The hospice population in inpatient units may be changing and this further challenges the provision of psychosocial care to different types of patients. Mor (1987) identified the difficulty in providing psychosocial care to patients whose admissions were ten days or less. Saunders (1990) noted that admissions averaged three weeks. These patients have had one previous admission to the unit.

## Summary

If hospice caregivers previously were unable to provide psychosocial support when admissions were short, are they able to when stays are longer? Patients who are admitted to inpatient units more than once are more likely to be alert and aware of their surroundings. Do their caregivers take into account the dying and deaths they are exposed to?

Hospices recognised that terminally ill patients required special care and responded. By congregating dying patients in wards, rather than isolating them in side rooms, hospices ostensibly unveiled an element of the societal death taboo. They advanced pain management. Research suggested that terminal care is similar between hospitals and hospices because hospitals are adopting hospice practices. Have hospices made their contribution to terminal care?

Wilkes (1981) argued that in hospices 'the herding together of those soon to die is an unattractive concept, justified only because in fact it works surprisingly well' (p:186). Glaser and Strauss (1968) examined hospice principles practised in St Christopher's Hospice. They noted that patients were not moved out of wards into single rooms when they were near death.

Terminal care is provided in hospitals, hospices and now AIDS hospices. Traditional hospices are reluctant to admit AIDS patients. Further to the point, in recent personal communication with a hospice administrator, he acknowledged that a donor who made



significant financial contributions stipulated that none of the funds should be used to assist in the care of AIDS patients. Because hospices rely heavily on donations, these provisos are possible.

The gap between hospice ideology and care in practice is now discussed. Torrens (1981) and Weisman (1988) believed that hospice programmes have not documented whether the care made a difference to patients, although it is acknowledged as doing so. They questioned whether hospice care is superior to terminal care in other settings. Hospices' admissions are basically patients with cancer and MND. Douglas (1991) questions whether this exclusivity can still be justified. Young (1981) argued that hospices must evaluate the care they provide. Hinton (1981) argued that successes and problems in hospice care need to be explored, otherwise 'could hospices become rather isolated, inefficient dormitories for the dying we have seen before?' (p:32).

In reviewing hospice and hospital care for the terminally ill, Seale (1989) argued that both institutions provide adequate services. He believed that there are few differences between them. A misconception about hospice care is that it provides TLC during patients' last days. Many patients are discharged from hospices and their care may include many investigations and procedures that are usually associated with acute hospital care (Johnson et al, 1990).

Saunders (1990) noted the protracted admissions in hospices. These patients are mixed in wards with others dying. Earlier research



indicated the difficulties caregivers experienced working in the presence of dying patients. The practice of collective terminal care is challenged in this thesis.

### **Strengths and Weaknesses of the Research Literature**

Ultimately the objective of this literature review was to locate hospice care from its development of terminal care in hospitals. Research related to hospital care of terminal illness was abundant. The literature was weak in terms of research-based studies on terminal care in hospices. Saunders' principles of hospice care provided a baseline of information, as do similar hospice handbooks. Further research is necessary to examine hospice principles in practice because the field is so large. Pain and symptom control have been investigated by the medical community. Few other studies deal with the other issues of hospice practice. There are many articles about hospice care which are based on personal experiences, anecdotes and opinions, but because they are not research-based, assessing hospice care through these was limited.

### **Implications for the Present Study**

Hospices developed from unsuitable care for the terminally ill in hospitals. Hospices are believed to have influenced society's attitudes to death and dying. They offer holistic care - physical, emotional, social and spiritual. Yet, hospice-based research suggests, in practice, the priority was found to be physical care.

Psychotherapeutic benefits of patients communicating their attitudes towards death was identified in both hospital and hospice care. Research studies described that this was problematic to achieve in hospice practice.

Physical isolation of dying patients in hospital side rooms is perceived negatively. In this sense, then, communal care in open wards has recognised isolation as being problematic. However, research illustrated that hospice patients were bothered by the sight of dying patients in open wards.

In this study I chose to focus on dying and deaths in a hospice. These issues are important because they are central to and the eventual outcome of hospice care. Studies on hospices only examined these issues as a small component of hospice care. I believe they need to be explored in greater depth. By examining issues of dying and death, areas such as holistic care, communication and the consequences of open wards lend themselves to examination.

Patients' views are necessary to provide a representative picture of hospice care. Munley (1983) argued that she limited interviews with hospice patients because she believed that they were physically unable to endure intensive interviews. This point aligns with my view that terminally ill patients are a protected population because of their illness. This position is a reason for gatekeepers to limit researchers' contact with terminally ill patients. I disagree with Munley's view because interviews can take many forms which take into account patients' physical

limitations. This study reveals that sporadic conversations, as informal interviews, are possible with terminally ill patients. Hospice literature places patients first, so I was led by previous research to focus on a study of patients' views.

## CHAPTER 3

### ISSUES IN FIELDWORK : METHODOLOGY

## Introduction

This chapter deals with epistemological issues and the methodological approach that was adopted for this qualitative study. The issues introduced in this chapter are for the purpose of my argument. The purpose of the following review is to explain the background which was then modified during the fieldwork. Data were collected by means of participant observation. Particulars of the fieldwork are discussed in Chapter 4.

Documentation of patients' and others' experiences in connection with dying and death in a hospice inpatient unit provided data for this study. This qualitative study has been informed by symbolic interactionism, especially the work of Mead (1934) and Blumer (1969). Symbolic interactionism is discussed in the second section. In the third section the issues related to ethnography are presented. The section on positivism and *verstehen* contrasts these approaches. The work of Hammersley (1990) is drawn on extensively for discussion of ethnographic-related issues because his work is particularly pertinent to the development of this study. The purpose of theory and grounded theory are also discussed.

## A Qualitative Research Approach

Qualitative research examines the social construction of meaning. Weber's (1947) discussion of *verstehen*, understanding, leads us to an interest in the meaning of action from the participants' point of view. *Verstehen* approaches include: observing, generating

hypotheses, illuminating and describing. Weber studied human behaviour from the actor's own perspective (Bogdan & Taylor, 1975). Human behaviour takes place in naturally-occurring settings which are observed or recorded first hand (Silverman, 1985).

Qualitative research approaches use many data collection techniques, including extended fieldwork and provide understanding (*verstehen*) from the actor's point of view (Bulmer, 1977). Hammersley (1990) argued that 'the research process is inductive or discovery-based rather than a being limited to the testing of explicit hypotheses'. Instead, interpretive research has a 'general interest in some type of phenomena in some theoretical issue or practical problem' (p:8). The focus of this study is narrowed to the management of death and dying in a hospice which is part of a much larger field of terminal care.

Qualitative research methods can be descriptive and exploratory. Qualitative research is inductive and works from the particular to the general, whereas quantitative research is deductive and works from the general to the particular. Qualitative research deals with individual situations, with events and phenomena which either occur infrequently or which are purposefully examined in isolation. It examines phenomena in depth in order to understand the meanings of situations for the individuals involved in them. It may result in identifying certain patterns leading to hypotheses or advancing general theories which can then be tested deductively. Qualitative research develops theory inductively from the data (Denzin, 1989).

The following discussion examines Weber's concept of *verstehen* and how it relates to the former section.

### **Positivism and *Verstehen***

The purpose of this section is to contrast the two research approaches, positivism and *verstehen* and to describe the latter in depth. This study falls within the *verstehen* approach. Symbolic interactionism guides the study. Symbolic interactionism is presented in the next section.

Positivism seeks causes or facts of phenomena without regard for the participant (Bogdan & Taylor, 1975). Positivism and phenomenology demand different methodologies, Bogdan and Taylor go on to say. The positivist approach views natural and social sciences as sharing a basic methodology because they adopt certain research procedures which arrive at theories and explanation.

Weber (1946) believed that natural and social sciences differ and required different research approaches. The scientific method or positivism produces so-called objective knowledge. Positivism explores the content of what actors say, whereas interactionism focuses on what people are doing and saying (Silverman, 1985). Positivism suggests that social sciences should be like natural sciences, where facts and causes are objective (Bulmer, 1977). Bulmer argues that positivism records empirical observations from a subject-object approach, detached from interaction.



With positivism, theories are rigorously tested, confirmed or falsified by data subjected to various analytical tests. Survey and experimental research fall within the positivist domain. They utilise standardised procedures which theoretically produce neutral observations of events which prevent researcher bias and subsequent contamination of the data. Thus positivism is viewed as objective and it holds that inter-observer observations are achievable which strengthens the reliability of findings.

'Positivist sociology seeks causal explanations of social phenomena'. Positivists separate 'themselves from the worlds they study' (Denzin, 1989b:24-25). Positivism in sociological research assumes that events are objectively measurable through the collection of quantitative data drawn from the world under study. By objectifying the observational process, this model divorces the researcher from the world under study. Positivism presumes that social processes operate within a cause and effect paradigm. Positivist research asks the 'why' question (p:23-24). It 'presupposes a theoretical-analytic conceptual framework that stands independent of the world of interacting individuals' (Denzin, 1989b:25). Quantification of facts and variables and their relationships are deductively established. The quantification facilitates statistical explanations of the data. The standardised procedures promote replication of the research which increases the reliability of the findings. The qualitative research is more interpretive (Bruyn, 1966). Now the *verstehen* approach and how it applies to this study will be discussed.



Weber (1947) discussed the subjective experience of interpretation. Weber's approach involved substantive problems and the methods to study them (Bruyn, 1966). He called for a balance between causal analysis and interpretive understanding which is problematic because this balance is impossible. He was concerned with meaning and the meaning of situations as defined by individuals (Silverman, 1985).

Understanding is available in observation and as explanation or interpretation. '*Verstehen*' is understanding the meaning of human action from the actor's point of view, so as to explain human action (Silverman, 1985). *Verstehen*, Giddens and Turner (1987) argue, 'is meaning' (p:4). Qualitative research draws on actors' understanding as a first-order topic for sociological investigation. It uses many techniques, including fieldwork, to obtain the actor's understanding (*verstehen*) and establish patterns of interaction (Bulmer, 1977). *Verstehen* and common-sense knowledge are linked.

*Verstehen* in the form of common-sense knowledge and discourse about social reality is important to the actor's development. It is the means by which living in the social world is negotiated. The actor engages with this understanding as well as with other actors. Thus *verstehen* is achieved by socialisation (Berger & Luckmann, 1966). Through socialisation the actor absorbs knowledge and learns acceptable and unacceptable modes of behaviour and discourse. Socialisation is a continual interpretation of the social world and the absorption of that interpretive knowledge within the consciousness of the actor. The processing of this knowledge



occurs through what is already known, or taken-for-granted with new knowledge. Common stock of socially constructed knowledge occurs by continual adjustment of the new knowledge. Contradictive knowledge and discourse may be held by actors engaging in different spheres of social experience.

*Verstehen* is a set of knowledge and discourse that is the basis of discourse and action. This knowledge is held in space and time, that is in a relationship with the social world through intersubjective processes. Thus the actor is continually faced by social life as it emerges and is amended as the actor engages in it.

The method necessary for the subjective approach must reflect the actor's perspective. Fieldwork methods are based on Weber's (1946) '*verstehen*' or understanding. He believed *verstehen* was necessary for interpretative understanding. Johnson (1975) argued that fieldwork research is a subjective approach. It strives for representativeness in observations. Humans have to make sense of situations in interactions, to act accordingly. *Verstehen* incorporates subjective perspectives of human experiences.

Weber believed that all research is contaminated to some extent by the values of the researcher. Conclusions and implications to be drawn from a study are largely grounded in the moral and political beliefs of the researcher. The initial choice and conceptualisation of a problem, as well as the subsequent attempt to seek practical implications from its study, were highly 'value-relevant' (Silverman, 1985).

Positivism, as outlined earlier in the chapter, adopts an objective approach to the research enterprise. I chose to adopt a *verstehen* approach to conduct this study. One contributing factor was that it seemed necessary to establish a firm relationship with patients before sensitive issues could be discussed. *Verstehen* offered a human element to dying and death. *Verstehen* builds the subjective into experience which includes actors and the researcher. With *verstehen*, understanding is available in direct observation. My voice in this thesis is supported by the participants' views and experiences and my experience, on which judgments of practice were made. Explanatory understanding is integral in the interpretive approach to data. Such understanding is achieved by getting close to the data such as with participant techniques. These techniques are described fully in the next chapter. The analysis and 'grounded theory' used in this study are discussed later in the chapter. Participant observation is historically related to anthropology. It constitutes a distinct method which characterises all field studies (Bruyn, 1966).

### **Symbolic Interactionism**

Symbolic interactionism is linked to Mead (Bogdan & Taylor, 1975). It is a social psychological perspective which informs empirical studies of human interaction (Lindesmith & Strauss, 1969). Symbolic interactionists distinguish between animal and human behaviour by human's possession of a mind. The symbolic interactionist perspective and the research strategy of participant observation are linked. In Chapter 4 the method of data collection is described. First the interactionist perspective is discussed.

For symbolic interactionists, people are in a process of interpretation and definition of situations (Bogdan & Taylor, 1975). A situation has meaning, they claim, through people's interpretations and definitions. Their action results from meaning.

Symbolic interactionism is based on the work of the sociologist George Herbert Mead (1934) who was instrumental in its development and was aided by his student Herbert Blumer (1969). Symbolic interactionism and the work of Mead is the perspective of this study. The Chicago School represents the work of Mead and his attention to process. This School produced quasi-ethnographic studies. Its theoretical framework was rooted in the social philosophy of pragmatism. Pragmatism is a philosophy of action. The Chicago School placed emphasis on empirical research (Joas, 1987). Robert Park, a student of Dewey, produced first-hand descriptions that did not test hypotheses or involve theoretical generalisation. Park's work is referred to throughout the thesis. The Chicago School emphasised subjective aspects. Blumer strived 'to make modern society intelligible' (Meltzer, 1975:57). Its methodology is sympathetic to introspection. This intuitive *verstehende* approach emphasises intimate understanding more than inter-subjective agreement among investigators. Blumer developed the relation of the social scientist to the object of their investigation. He developed social research of subjective experiences. He advocated use of theoretical concepts that were sensitive to empirical reality (Joas, 1987).

Symbolic interactionism is an interpretive approach (Wilson, 1970). It is a process that forms action. Interaction in humans acting on one another and through it mutual action emerges. Interaction is symbolic and uses the element of language. Language is an expression that enables subjective definition and interpretation of situations. Bruyn (1966) points out that language is a significant phenomenon which bears upon the social meanings in a study. Through language subjects define and interpret their world. Language is part of the process of socialisation and enables the subject to know their world and their possible courses of action. Through communication with others the self emerges. It is more than taking in the communication but of interpreting the intended meaning of it (Blumer, 1969).

The following premises are common to symbolic interactionism. 'First, human beings act towards things on the basis of the meaning that the things have for them. Secondly, these meanings are a product of social interaction in human society. Thirdly, these meanings are modified and handled through an interpretive process that is used by each individual in dealing with the signs he/she encounters' (Meltzer et al. 1975:1).

Individuals and society are in a 'mutually interdependent relationship'. Society is comprehended in terms of the individuals that comprise it and individuals are understood from the standpoint of the society they belong to (Meltzer et al. 1975). The researcher observes the actor's point of view and their interpretation of behaviour on the basis of the actor's understanding (Mead, 1934).

Humans are self-reflective beings. Their behaviour is not caused by forces from within themselves but instead from a reflective and socially derived interpretation of the internal and external stimuli that are present. The environment's influence resides in their social meanings.

Early interactionists argued that individuals could never be understood apart from the social situations in which they were participating selves (Blumer, 1969). Meanings are derived from things. 'Symbolic interactionism uses meaning as arising in the process of interaction between people' (Blumer, 1969:4). 'Thus symbolic interactionism sees meanings in and through the defining activities of people as they interact' (Blumer, 1969:5). 'Thus the use of meanings by the actor occurs through a process of interpretation' (Blumer, 1969:5). The researcher must understand the actors through their interpretations of events because actors know their inner state (Blumer, 1954). Early interactionists believed that human behaviour is accumulative and constructive. Their acts, responses and perception were built upon those present in our social repertory (Meltzer, 1975). 'Meanings are handled in, and modified through, an interpretive process involving the things he encounters' (Blumer, 1969:2). Reality is created in the empirical world and understood in joint interaction (Denzin, 1989).

Social control and co-operation that is necessary in society depends upon the degree to which individuals assume the attitudes of others in society. Individuals were seen as reflective or interacting units which comprise the societal entity. To understand the individual's behaviour, one had to interpret and

inspect their social environment for the 'conditions of social interactions' (Meltzer, 1975:43-433). Symbolic interactionists believe that society is 'held together by shared meanings' (Meltzer, 1975:50).

#### Interactionist methodology

Blumer's advocacy of a special methodology lays heavy emphasis upon the need for insightfully 'feeling one's way inside the experience of the actor'. The student of human conduct, he contends, must get inside the actor's world and must see the world as the actor sees it, for the actor's behaviour takes place on the basis of his/her own particular meanings ... and must attempt to use each actor's own categories in capturing the actor's world of meanings (Meltzer, 1975:58). This is achieved by specific techniques such as observational techniques like life histories, autobiographies, case studies, diaries, letters, interviews (especially of the free, or non-directive, type) and, most importantly, participant observation (Meltzer, 1975:58).

Blumer criticised 'experimental, instrumental and quantitative methodology as detached observation from the outside' (Blumer, 1969:58). He believed they could understand the meanings that determine how individuals respond to objects and situations. Blumer objected to operational definitions of concepts in research. He proposed 'sensitising concepts' that offered directions along which to look (Meltzer et al. 1975).



Humans direct their actions to handle situations on the basis of what they take into account. Mead recognised that interaction is a 'conversation of gestures'. People signal their respective courses of action (consciously and unconsciously) by gestures, and at the same time, they interpret the gestures of others. Out of this simultaneous process of signalling and interpreting, people adjust their respective lines of conduct, with the pattern of such an adjustment being a function of the motivational process (Turner, 1987). Mead noted two forms of social interaction as 'the conversation of symbols' or 'symbolic interaction' (Blumer, 1969:8). Non-symbolic interaction occurs when an individual responds to another's action without interpreting that action. Symbolic interaction occurs with interpretation of the action. A non-symbolic interaction is like a reflex response. Symbolic interaction, according to Mead, is a presentation of gestures and a response to the meaning of those gestures. A gesture is part of an ongoing action that signifies the larger act to which it belongs. The gesture has meaning for the person making it and the recipient of it.

According to symbolic interactionism, collective life is a process in which objects are being created, transformed and tossed aside. Social life consists of confronting situations in which they have to act and their action is based on what they note, and how they assess and interpret what they note, and what kind of projected lines of action are available to them (Blumer, 1969). Symbols stand for something else. It requires that one abstract and recall that which the symbols stand for. Words can be understood as symbols (Bruyn, 1966). Emotive symbols may begin as signs.



Expressing pain or surprise are examples of emotive signs. Spiritual symbols are also abstract and reflect the development of a person's sentiment like states of suffering and joy (Bruyn, 1966).

#### A naturalistic approach

The naturalistic approach records human behaviour. It implies that social events and processes are explained with reference to their relationships with the context in which they occur. Bruyn (1966) wrote that in the 1930s, Znaniecki believed that if the researcher tried to study a cultural system as though it existed separately from human experience, the system would disappear and be replaced by 'a disjointed mass of natural things and processes'<sup>in</sup> which similarity to what was studied would be displaced and misrepresented' (p:10). To explain human actions demands gaining an understanding of the cultural perspectives on which they are anchored. This is why participant observation and informal interviewing are central to the ethnographic method (Hammersley, 1990).

The procedure of analytic induction, which is discussed later in the chapter, is attached to naturalistic social inquiry as an interplay of theory and method. Propositions are ground in empirical observations and tested with further observations. These worlds become intelligible through a theory grounded in attitudes and behaviours of its participants.

This section dealt with how interaction incorporates the

individual's socially derived interpretive processes. It has demonstrated that interaction is a complex and simultaneous process of signalling and interpreting to arrive at meaning. The material on interactionism is closely linked to the practice of participant observation that is discussed in the next chapter and is applicable to Chapters 5, 6 and 7. The data are dissected into two phases, conversational and narrative. The conversational data are presented as interview data. With the narrative data, a contextually richer representation is provided which enables the reader to become part of the scene that is depicted.

### **Issues Concerning Ethnography**

The scope of ethnography is diverse and includes interpretative research, case study, participant observation and life history method (Hammersley, 1990). In the following sections I discuss ethnography and related issues since several of its techniques were used in this study. This section outlines the data and analysis through to theory generation. Ethnography is defined in a way which includes the role of description and explanation. Ethnographic writing is included and how it is assessed. Constant comparative analysis is covered and analytic induction precedes coverage of grounded theory.

### **Ethnography**

The following characteristics, Hammersley (1990) argues, are common to ethnography: (i) people's behaviour is studied in their own contexts, rather than under artificial experimental conditions

created by the researcher; (ii) data are gathered from several sources, but observation and/or relatively informal conversations are common to it; (iii) the data collection is relatively 'unstructured' so it does not involve a complex plan nor are categories used for interpreting what people say and do pre-determined. This does not mean that the research is unsystematic, instead initial data are collected in a raw form and on a wide front; (iv) the focus is primarily a single setting or a group on a small scale; (v) the data analysis involves interpretation of the meanings and functions of human actions and includes descriptions and explanations, with enumeration and statistical analysis subordinated. Ethnography is suited to processual and meaning-laden characteristics. It is suited to small size studies. This study is confined to one hospice inpatient unit.

Interactionist ethnography is concerned with the creation and change of symbolic orders in social interaction. The interactionist views research as a symbolic order based on interactions. Methodology for the interactionist is the way the sociologist acts on his environment. Interactionists are in a subject-to-subject relation to their data (Silverman, 1985).

Material from observations, interviews and documents are data sources (Schatzman & Strauss, 1973). Ethnography includes focused observation, indepth interviews and participation in a setting. It is a systematic process of observing, detailing, describing, documenting and analysing patterns of people in their environment (Leininger, 1985).

### The nature of knowledge

The following sections explore what constitutes knowledge and how it was derived in this study. 'According to a dialectical view, knowledge is a creation of fieldworkers. As such it is created first of all in the interaction between fieldworkers and those whose ways of living they try to understand. In a wider sense of knowledge it is created in the interaction between fieldworkers and the whole situation in which they find themselves. The dialogue is continued after the fieldwork proper is over. It means that fieldworkers are a part of the knowledge and that this should be recognised in ethnographic description' (Burgess, 1988:228).

'Scientific method is not understood simply as meticulous and painstaking collection and analysis of data, but involves concern with theoretical problems and an urge to explain social phenomena through theoretical work' (Bulmer, 1977:2).

Social reality is experienced through symbols and is established through symbolic interaction. Interactionism 'fits the empirical nature of the social world'. Silverman (1985) argues that interactionist work is good descriptive journalism. Denzin proposes that description of content serves only as a prelude to analytic work. Denzin believes that the fascination of much ethnographic data should be a prelude to establish 'universal interactive propositions' (Silverman, 1985:104). Participant observation involves sharing in people's lives and learning about their symbolic world.

Ethnographers reject the conventional scientific model and emphasise ethnography's parallels with literature (Hammersley, 1990). 'The narratives and descriptions of ethnographies and the interpretation are woven together in a highly contrived product. These are all elements placed within a context of persuasion. Beyond the propositional content and the conclusions or findings to be presented, the ethnographic text strives for plausibility of its account. This does not detract from its scholarly status or merit. As we shall see, even the most scientific of accounts depends upon rhetorical, persuasive features' (Atkinson, 1990:2). 'Science is itself a rhetorical activity, and the scholarly and the literary share common conventions in the production and reception of their texts' (Atkinson, 1990:10).

To an extent, therefore, factual and fictional accounts are equivalent. There is not one set of conventions for literature and one set for science or scholarship: there may be differences, but they are by no means absolute. In this sense, then, science and literature share common discourse of textual convention. Some 'factual' accounts are close to some varieties of literature (for example, history and biography); one can think of other varieties of text which are very different (such as a report of a scientific experiment and a lyric poem). The recognition of such similarities and differences reflects the 'literary' competence of members of our society (Atkinson, 1990:39). If the sociologist is present when speech is produced they play a role in the creation of dialogue. If mechanical recording is unavailable to them, they 'invent at least some of what they report' (Strong, 1983).

The sociologist intending to obtain the complexity of social interaction and social process is himself seeking both to understand and explain social phenomena (not merely to describe them), and is interpreting the world, moreover, through a frame of reference of some kind, even if this is based on the view that facts can speak for themselves (Bulmer, 1977).

#### The objective of ethnography

The purpose of ethnographic studies is the description of how people understand and give meaning to their experiences. The goal of this inductive analysis seeks to develop theories about the use of language, values, beliefs and actions of people in their environments. Ethnography attempts to explain the meaning of commonsense aspects of the environment being studied. This is accomplished by the researcher familiarising himself with the members of a culture in which the research becomes part of that environment (Hunt, 1991).

The ethnographer focuses on a broad and detailed view of people in their environment. The ethnographer documents, describes and analyses aspects of a setting that influences people's lives. Ethnographers depict life that is grounded in people's experiences and general phenomena. Ethnographic data produces theories that are grounded in empirical data (Glaser & Strauss, 1967). The data can be used to provide insight, interpret behaviour or to guide changes (Leininger, 1985).



The range of outcomes of ethnography is wide. The product of research varies between authors and depends upon the researcher's intentions. Depending on the purposes of the investigator, the final conclusions drawn in research can vary greatly by level of abstraction. At lowest levels, they can be 'descriptive', and at highest levels, the researcher may aim for the generation of theory. A 'low level' description may only reproduce the informants' own words or recording their actions; reporting may be at a much more complex, systematic, and interpretive level and resulting in social theory which may be either broad or narrow in scope (Pollock, 1991). Low-level theory deals with factually exact minutiae (Bensman & Viditch, 1960). Data and the interpretation of data are often bound up together (Bulmer, 1977). This study aims to describe at a low level of theory and relate it to other sociological theories. My research fits both a general and specific level. Most of the data is specific and context-oriented. Bulmer (1977) also identifies what this type of research offers. Interpretative procedures such as the techniques of participant observation, offer a richness, colour and depth of description that few other social research methods enable. 'Following Schutz, second-order sociological accounts will have an analytic purpose that may be irrelevant to the members' first-order concerns. Instead of relying on direct comparison of these accounts, the aim is to discover whether members understand and accept the researcher's accounts. For the ethnographer consequently, his second-order analysis is merely a first-order analysis dressed up' (Silverman, 1985:46).

Some claims in ethnographies may be so plausible that they need no support. Many are not. When a claim is insufficiently plausible to be accepted, the next step is to assess its credibility. If we find a claim very plausible or highly credible, then that should be adequate to accept it without further evidence. However, if we assess a claim to be neither sufficiently plausible nor credible, then we must look for further evidence to support it (Hammersley, 1990:74).

#### The role of description and explanation

Current ethnographic studies deal mainly with description and explanations. Ethnographers intend to make theoretical inferences although this does not mean that the case examined is necessarily representative. The objective is not concerned with empirical generalisations (Hammersley, 1990).

Descriptions are the types of argument involved in ethnographic texts. The description becomes a verbal representation of some aspects of a setting. Descriptions provide accounts about the features of some type of phenomena that exists or existed in some place and time. The ethnographer's observations are included in extracts from fieldnotes. Informants' accounts may be presented as a form of interview (Hammersley, 1990).

Hammersley continues that ethnography presents 'analytic, thick or theoretical description' (p:19). The description combines hypotheses, interpretations and conclusions that are woven into the account as part of the description. This description incorporates



context of accounts and is interpretive (Denzin, 1988; Fetterman, 1989). The description encompasses the participants' interactions and the researcher's interactions with them. This method includes substantive observations of the events and people involved to levels of interpretation in interaction, observation and recording (Geertz, 1973). This type of description is especially noted in the narrative of the data chapters.

Thick description incorporates overt interactions of subjects and researcher's interactions with them. The method involves substantive observation of the events and people involved to levels of interpretation in interaction, observation and recording (Geertz, 1973). The objective of this study is to provide a plausible story of people and events in the hospice.

The context of the account states the intentions and meanings that organise the action. It traces the evolution and development of the act. It presents the action as a text that can then be interpreted (Denzin, 1989:33). 'The account is written in such a way to give the reader the impression that he or she is observing the scene described' (Hammersley, 1990:18). Several accounts were written in this thesis with the intention that the reader can become immersed in the event.

Explanations determine why some features occurred and intended to show that they were the result of particular factors with temporal and spatial locales, either direct or indirect. Descriptions and explanations both make reference to specific phenomena that are occurring in specific places at specific times, as do empirical

generalisation although these may be in many places and at many times (Hammersley, 1990).

Thus the conclusions drawn in ethnographies need to be examined as to whether theoretical inference or empirical generalisations, or both, are made. With empirical generalisations, we must explore for indications of the larger whole to which the generalisation belongs and for the reasons why and how such generalisation is possible (Hammersley, 1990).

Determining the validity of generalisations goes beyond the assessment of the claims. The main arguments of an ethnography are available in the summary the researcher provides (Hammersley, 1990). Description and explanation in sociology is such that research is chiefly inductive and the research intention consists of making inductive inferences from the data.

### The writing

Van Maanen (1988) refers to what he calls the 'impressionist style' of ethnographic writing. It provides vivid accounts of events witnessed and participated in. This type of writing incorporates dramatic recall. Events are noted in the order they are said to have occurred and includes bits of information that are part of remembered events. Strong (1983) argues that qualitative sociologists like other journalists and novelists employ various literary devices. He believes they 'commonly exaggerate for dramatic effect'. This, he continues, is useful during the preliminary stage of hypothesis generation. The objective is to

draw the audience into an unfamiliar environment and allow them to experience what the fieldworker experienced. This places the audience in an unfamiliar environment.

The author becomes involved in a complex set of 'readings' - of observations and inferences. They seemingly become the personal narrative of the ethnographer, who constructs this textual 'reality' from the shreds and patches of appearances and verbal testimony. Even though the informants speak, their authenticity is warranted by the ethnographer's incorporation of them into the definitive record (Hammersley, 1990:61). To make ethnographies comprehensive, they may be organised by chapters where the chapters follow stages in a process (Hammersley, 1990). Likewise, titles go beyond introducing the subject-matter and the contents that follow. Some titles may require closer inspection of the text because they explicitly reveal their subject-matter to the reader. The organisation and contents of titles may reflect rhetorical or literary features of the ethnography itself. Ethnographic titles may also reveal more general features of the rhetoric of ethnographic argument (Hammersley, 1990). The chapter titles in the thesis are part of the process of understanding dying and death in this hospice.

#### Assessment of ethnographic research

The assessment of ethnography is to outline the perceptions and interpretations of people and perhaps also to document the cultural resources by which these were produced. More commonly, the phenomenon being described goes beyond the participants'

understandings and includes their behaviour and the wider context. On both interpretations, though, the appropriate criterion of assessment is the extent to which the people's perspectives and/or early interpretations of behaviour and context are accurately represented (Hammersley, 1990). Data in this thesis were understandable to some key informants. The later stages of interpretation may be less so.

Although 'validity' and 'reliability' are generally associated with the quantitative approach and '*verstehen*' or understanding of behaviour with the qualitative approach, they are included in this discussion since the concepts have been adapted for qualitative research. Perhaps more relevant is the 'plausibility' or 'representativeness' of a study.

Validity in qualitative research 'refers to gaining knowledge and understanding of the true nature, essence, meanings, attributes and characteristics of a particular phenomenon under study' (Leininger, 1985:68). Validity is based on intent and reality. To have validity and work related conclusions, participants' accounts must be in their original meanings and must be similar (Bruyn, 1966).

Reliability is based on the fact that the study can be repeated and that it is possible for two people to perceive the same meaning by using the same categories and procedures (Bruyn, 1966). Reliability in qualitative research 'focuses on identifying and documenting recurrent, accurate and consistent (homogeneous) or inconsistent (heterogeneous) features, as patterns, themes, and other phenomena confirmed in similar or different contexts

(Leininger, 1985:69). The researcher assumes that their categories of knowing can be developed from theory and that their study may become relevant to existing concepts of meaning (Bruyn, 1966).

Hammersley (1990) describes 'validity' as 'truth': interpreted as the extent to which an account accurately represents the social phenomena to which it refers (p:57). The notion of truth is, however, problematic. 'Truth implies the possession of knowledge that is absolutely certain (that is proven beyond all possible doubt), yet knowledge can never be certain in this sense. A second source of problems with truth arises from beliefs about the nature of human social life. There are those who hold that in the case of social phenomena there is no single reality to which ethnographic claims correspond except to the one they represent. Social worlds involve the construction of phenomena rather than their mere discovery' (p:59-60). Assessing the validity of ethnographic claims includes examining the plausibility of a claim. Whether it is assessed as being true given our knowledge. Whether the assessment related to the claim is accurate 'Given the nature of the phenomena concerned, the circumstances of the research, the characteristics of the research etc' (Hammersley, 1990). This Hammersley refers to as 'credibility'. 'Where we concluded that a claim is neither sufficiently plausible nor sufficiently credible, we require evidence to be convinced of its validity. We will then have to assess its validity as we applied to the claim itself: we shall judge its plausibility and credibility' (Hammersley, 1990:61-62). Webster (1982) writes about dialogue and fiction in ethnography, he distinguishes between truth in ethnography and fiction. He argues that ethnography 'is taken to intend truth'

whereas realistic fiction 'encourages a suspension of doubt' (p:102).

Now I will address interviews or conversations and observations as problematic sources of data. Conversations are social encounters which develop into interactive and intersubjective practices which incorporate the context of events. Conversations represent experiences or understandings to which they refer. Thus *verstehen* is contextual but also historically linked to a moment in time, through which it is filtered. The conversation is thereby viewed from the context of the present. In the same way, observations are historically linked to the moment in time that they represent. They are snapshots of the scene they depict. They cannot be replicated but are representative of it. The researcher assumes that their procedures of knowing can be developed from theory and that their study may become relevant to existing concepts of meaning (Bruyn, 1966).

With ethnography, Hammersley and Atkinson (1983) point out that its purpose is to obtain a credible explanation of the data and relate it to a theory generated from the data. In meeting the criteria for plausibility, heterogeneous or negative items of data were included in the study because they enabled portraying a more representative picture of the hospice. Negative items of data were discussed and categories were subsequently modified.

## The Purpose of Theory

Two views of theory, the naturalistic and analytical, are discussed in this section. This study follows the naturalistic approach.

Theory may be abstract statements that are designed to fit some portion of the real world. It is an abstract way of representing events in the world that incorporates a hypothesis. The hypothetical constructs relate concepts integrated from empirical observations. The concepts are fit in the theory to events in the world (Zimbardo & Ebbesen, 1969).

'Theory is not about a reality out there, but rather it is a product of scientists' interests or their sense of aesthetics. A variant of this criticism is that theories are never tested against the hard facts of an external world because the facts themselves are also related to the scientists' interests and to the research protocols that are politically acceptable to a scientific community' (Turner, 1987:159). The goal of all theory is 'to explain how the social universe works' (ibid.:162). Explanation can be used to interpret some specific empirical process. These interpretations are of two basic kinds: when the location of an empirical event in a category system is found, then the empirical event is considered to be explained, or, when the scheme results in constructing a descriptive scenario of when and how events in an empirical situation occurred, then these events are considered in the explanation.



These different views of explanation by analytical schemes reflect the contradictory approaches: 'naturalistic and analytical schemes' and 'sensitising analytical schemes'. Participant observation data consist of humanising meanings interpreted through the observer's communication with participants. The observer seeks to discover and explain the nature of a particular sociocultural reality. They seek to discover what the world means to participants (Bruyn, 1966).

#### Constant comparative analysis

The model of fieldwork and analysis used in this study is based on the work of Glaser and Strauss - the discovery of grounded theory (1967; 1978). The constant comparative method is the central feature of the grounded theory approach where data collection and analysis are undertaken concurrently. Glaser and Strauss do not make any formal distinction between stages of the research process.

The researcher enters the field with a general and tentative research problem in mind and a theoretical perspective that informs the problem. However, Glaser and Strauss stipulate that the outcome of fieldwork is not to test a specific hypothesis. Instead, the hypotheses emerge from qualitative research, hence this type of research is flexible and allows for directional change. The research problems develop and become more focused as the fieldwork progresses. The concurrent nature of the fieldwork is such that data are being gathered and analysed while emergent patterns are being recognised and focused on. As the research continues, the definition of what is significant becomes clearer.



The direction of these different stages is relatively orderly. Each item of data is coded and compared with other pieces of data soon after it is collected.

There were three stages to this study. In the pre-fieldwork stage a review of related research was undertaken and a sensitising concept was generated from the literature, as was a general research problem which was identified and defined and revolved around the sensitising concept. The sensitising concept is discussed in detail in the next chapter. The second stage involved participant observation and analysis. The third stage was the write-up where theme identification and development proceeded alongside the writing. During the writing it became apparent that the themes of death and dying were distinct and that writing them as one theme did not work. Thus they were separated into separate themes.

Glaser and Strauss note that in qualitative research the researcher works through many informal hypotheses during various stages of a study. The sensitising concept served the purpose of an informal hypothesis at the outset of the fieldwork. However, the sensitising concept was turned on its head during the analysis and write-up and converted to the theme of Chapter 5. Glaser and Strauss continue that formal hypotheses emerge from the process of interpreting and analysing data, which was the case in this study, as outlined in the previous paragraph. Data collection, induction, deduction and interpretation are concurrent and form part of each step of the research process. During the fieldwork interpretations are preliminary and may be modified during the write-up stage of

the research process.

As data were obtained, then semi-formal hypotheses were formulated. These hypotheses relate to data itself and were not artificially imposed on the data. They pertain to categories that were suggested by the data and refer to how *verstehen* was organised. Standardised procedures of data collection and hypotheses identification do not occur with this method. Instead, the nature of qualitative research makes it possible to relate the participant observation to the participants' sphere or social world.

Glaser and Strauss make no mention of a cut-off period in fieldwork when formal data analysis begins. They speak of phasing from the fieldwork to the analysis. Analytical decisions are made during the entire fieldwork period and following it. However, in this study a more intensive period of analysis began when the fieldwork was completed. The objective was to make sense of the field notes, interpret and explain them. Three general themes were identified in the data and are separated as chapters in the thesis. The themes were further explained by sub-themes.

The researcher inductively develops a hypothesis that is deduced and verified or disconfirmed by the data. Constant comparison is the primary method of data analysis used in theory generation. This method entails comparison of incidents with other incidents when forming categories (Silverman, 1985). Constant comparison enables discovery of dominant processes and structures the analysis. Items of data are checked against similar data (Glaser & Strauss, 1967). All data are examined for their applicability to

category development. Here the distinguishing between the themes of death and dying are noteworthy. Once this discovery was made, writing about the categories proceeded in a more orderly fashion. Initial categories are formed, augmented or reduced. Once these categories were separated, proceeding with defining each category became more orderly. Incidents in each category are compared. Categories and their properties are integrated once they are identified as distinct from other categories. Properties or component parts, define and explain the category. They support the development of a category. The integration of categories and properties enables the fullest representation of the category.

The researcher develops generalisations that hold across the data (Bulmer, 1977). Theoretical sampling involves letting the emergent themes direct the data collection. Negative cases allow combining empirical data, concept, proposition and theory. Negative items of data may influence a category or may be built into a hypothesis. Negative items of data may disconfirm previous data but are invaluable because they provide an alternate point of view. Negative items are important because they exemplify reality, where all members are not in agreement and are more representative of reality. The hypotheses must be revised if the negative cases are unexplainable (Denzin, 1978).

Constant comparative analysis was relied on during the fieldwork and following it. Line by line coding was conducted on the expanded field notes. Data were assigned to developing themes. Negative cases were taken into account during the theme development. The themes were augmented by data from multiple

sources which are discussed in the next chapter.

### Grounded theory

This section begins with analytic induction because it is linked with grounded theory. Grounded theory is theory grounded in data. Qualitative research enables developing hypotheses. It allows a small number of cases to be developed into a hypothesis which can be examined in greater depth. Znaniecki (1934) believed that this could lead to specific knowledge under investigation and to causal laws. Denzin (1989) noted that the process of analytic induction allowed formulating and defining the phenomenon to be interpreted and hypothesised in studying a case with a view to determining whether the hypothesis fitted the specifics of a case. If the hypothesis did not hold, reformulating it was possible when several cases were examined. However, a negative case refuted the propositions and reformulation of the hypothesis was necessary. This process is ongoing, the redefining of the phenomena and reformulation of the hypothesis. Successful analytic induction requires a specific formulation of the hypothesis. Successful analytic induction requires a specific formulation of part of the problem (Strong, 1979). Analytic induction is a strategy of analysis that allows the researcher to formulate generalisations that apply to all instances of the phenomena. It enables generating propositions which attempt to cover every case that is analysed that leads to 'universal-interactive propositions' (Denzin, 1989:25). Analytic induction seeks cases that test a theory until propositions cover every case studied before the theory is complete.

Grounded theory is a process that involves both induction and deduction in constructing theory from concept, constructs and hypotheses arising from the data (Glaser & Strauss, 1967). Categories are identified that fit the data. They are the beginning of theoretical explanation. Categories are named and their characteristics are identified through their sub-categories which support the categories. Hypotheses are generated from the data they originate in. They may be modified throughout the fieldwork by induction and deduction with incoming data.

Induction is the action that leads to the development of a hypothesis. Hypotheses are provisional and conditional. Deduction is drawing implications from hypotheses for the purposes of verification by using the data or by going back into the field and determining whether that is partial total qualification or negation. Hypotheses that do not hold up under this verification can be a partial qualification or negation of the hypotheses. Constant comparison and analytic induction are where the researcher systematically deduces hypotheses from a body of theory and attempts to falsify them. Verification cannot occur without deduction. Deductions are made throughout the research process by way of theoretical questions, hypotheses, theoretical sampling and possible categories (Strauss, 1987). Theoretical explanations are grounded in data and formed and modified during the data collection. Negative cases demand reassessment of the proposed causal sequence or the interpretation is modified to take into account negative cases. The relevance of grounded theory is that the development of concepts formed are anchored in the context in which they occur.

Theoretical sampling leads the investigator to decide what data to collect and where to go next and facilitates the reformulation of categories. It does not rely on one type of data nor one technique. Glaser and Strauss (1967) refer to 'slices of data' which impart different views from which to understand a conceptual category and develop its properties. Theoretical sampling and constant comparative analysis are central to developing grounded theory. Theory generation begins with coding. Categories are produced from a number of substantive codes which are a higher level of abstraction than the raw data. Categories are generated from evidence which reflects a theoretical abstraction of what is happening in the study. Categories describe classes of events, individuals, situations or phenomena that have certain characteristics in common. Categories are similar to variables in quantitative research. Categories have meaning when they can be uniquely identified through their characteristics or 'properties'. Theoretical sampling yields new sub-categories related to the main category. Similarities and differences, resulting from theoretical sampling, between sub-categories are established. Data sources are identified and included in a study and linked with the constant comparative method of data analysis. Theoretical sampling either minimises or maximises the differences between the comparisons being made.

A main category of some phenomenon is identified and named. Related data from all sources are placed in that category. Sub-categories are established from coded data (Strong, 1979). A main category should be capable of explaining the variation in the data such as negative cases (Benton, 1991). A main category

repetitively appears in the data. It relates to other categories. A category is complete when no new data contribute to a category (Glaser & Strauss, 1967; Burgess, 1984). This is called 'saturation' by Glaser and Strauss. A category is saturated when the data no longer provide further properties and is completely developed (Benton, 1991). Once categories are developed, an abstract definition or conceptualisation begins.

Theoretical memos are derived from coded data. Memos are crucial to the grounded theory method. They are made in order to record thoughts, hypotheses and development of categories. Memo writing commences after the initial data have been collected and coding and analysing has commenced. Memos become more abstract, they include thoughts, views and questions or hypotheses. To develop grounded theory the data are handled without a preconceived framework. Data are explored for sociological and psychological processes. Grounded theory typically includes data collection, organisation and analysis. This process proceeds until detail, at a level of abstraction, explains the data. Categories describe, in conceptual terms, the data which forms the theory. This enables the findings to move from the descriptive to the explanatory. The process by which the grounded theory is produced is the constant comparative method.

Theories are formed of hypotheses, propositions and assumptions (Denzin, 1989). Induction, deduction and verification are central to the grounded theory process. Induction enables developing a preliminary hypothesis. Deduction assists explaining the hypothesis to verify it (Strauss, 1987). Theory should identify



the social and psychological processes which accounts for the variation in the data gathered. The theory should be dense and must be linked to existing knowledge and grounded theory must provide a plausible explanation (Benton, 1991).

The three themes in the thesis are categories. 'Displaying dying' and 'concealing death' became two themes while the third theme, 'responding to dying and multiple deaths' serves as the hypothesis.

Ethnographic theories tend to be flexible. They are tested, retested again all in the field. They also tend to be resistant to high level abstraction. They are tentatively asserted, full of reservation and qualifying detail (Van Maanen, 1979). Descriptive accounts encompass detailed description informed by theoretical schemes (Burgess, 1984). Theoretical constructs conceptualise the relationship between the codes and thread pieces of data back together (Glaser, 1978). Mixes of empirical observations and theoretical analysis are difficult to be separated. Analytic descriptions are conceptual schemes based on the data.

In this chapter I have discussed theoretical issues that pertain to this study. The discussions outlined the contending perspectives from which research can be examined, positivistic or *verstehen*, and the *verstehen* approach which was adopted in this study. Also presented were the symbolic constructions of interaction. The merits and questions about ethnography defined its parameters in relation to the development of grounded theory through analytic induction and constant comparison. In the next chapter the practice of the research illustrates the practicalities of the



fieldwork.

## CHAPTER 4

### ISSUES IN FIELDWORK

In this chapter I discuss issues related to the practical implementation of the methods of this field study, as introduced in the previous chapter.

### **Access Negotiations**

Access negotiations and related issues are presented in this section and I explain how the research site was located and provide a description of the research site.

#### Locating a research site

Managers from eight in-patient facilities in Scotland which offer hospice-type terminal care were contacted by letter to explore their interest in my proposed study on patients' views about hospice care. These facilities included independent hospices and palliative care units and continuing care units.

Seven facilities expressed interest in the study and meetings with managers were arranged. The eighth hospice had recently had a similar study conducted within it. The meetings were held at the respective facilities. Copies of the research proposal were either sent in advance or brought to the meetings. We discussed the proposal and issues the managers raised. Such topics included the possible content of conversations with patients and the psychological implications of these conversations. One manager was concerned that conversations might raise psychological problems and might upset patients.

At the time of access negotiations, it was planned to conduct the study in one site and possibly a second, depending on the amount of data collected in the first site and the remaining time left in the fieldwork. If two sites were used that would enable me to include some comparative elements into the study.

Factors considered in making a final decision as to the research sites finally selected included available accommodation for me and public transport nearby. These factors were crucial because the fieldwork would include evening and night shifts.

Four managers expressed an interest in the study being conducted in their facilities. They were informed that one site would be selected with the possibility of a second. The second site option was considered before the fieldwork began, when I was concerned that not enough data would be collected in the first site and considered the possibility of a comparative study. As the fieldwork commenced, the availability of data was not an issue. Thus I decided against the second site option. The advantage of two research sites was that they would have enabled a comparative element to the study. The disadvantage, however, was that with two research sites the fieldwork period would have been extended beyond the time and resources available to me.

#### Negotiations at the research site

Approval to conduct the study at the chosen research site was given by the medical and nursing directors during our second meeting. Ethical approval seemed implicit in the decision to allow me to

conduct the study in this hospice. Bogdan and Taylor (1975) identify that gatekeepers may set conditions for conducting the research. This did occur.

A condition of access was that conversations with patients could not be audio-recorded. At the time this condition was made I was disappointed. However, as the fieldwork commenced, it became apparent that taping short conversations with patients would have been an impediment to the conversational and episodic nature of the informal interviews with patients. As discussed later, recording conversations by hand proved to be adequate.

At the outset of the fieldwork, a presentation of the study plan was made to staff members within the hospice. Again, the issue of the content of conversations with patients was raised. One auxiliary believed a student previously on the unit discussed topics such as death with patients in an inappropriate manner. Another staff member suggested that broaching this topic allowed patients to discuss their views. My response to these issues were that the content of discussions with patients would not be known until we met and that patients would discuss what they were comfortable with. Also discussed were any plans for publishing the study. The staff members were told that the study was intended to be the basis for a PhD thesis.

A schedule of my data collection periods, which included the 24-hour cycle, in the hospice was drawn up and posted in the Duty Room. Separate copies were provided for the medical and nursing directors.

I liaised with the Nursing Director throughout the fieldwork and in her absence with the senior nursing sister. Issues discussed included the nursing director speaking with me about one complaint that was raised by a patient's daughter, who said that I had remained with her mother for over an hour. The director was not alarmed by this concern because the patient was a noted conversationalist and everyone in the unit was aware of this fact, including the director. The director was understanding about the daughter's complaint and told her that she would speak with me. She also discussed a patient whom she believed was unsuitable for me to speak with because she was denying her prognosis (0409:11). This fact did not hinder further conversations with the patient.

#### The research site

Work experience of one week was conducted in the research site a year before the commencement of the fieldwork. It provided a brief introduction to the hospice and its services, with a focus on the inpatient unit. It familiarised me with hospice care as I had not previously worked as a nurse in a terminal care setting. During that work experience, I worked as a volunteer nurse and assisted the staff members with patient care.

The inpatient unit consists of 30 beds and it has doubled in size since the hospice's early days in 1977. Twenty-four of the beds are in 4 wards. Six single rooms are available.

The medical staff are a director, consultant and senior registrar. They are assisted by the services of a part-time GP from the

community. The nursing staff of the inpatient unit are discussed later in the chapter. The Home Care Department is staffed by 4 MacMillan Sisters. They hold caseloads of up to eighty patients at a time. Bereavement services for relatives were provided and they include many disciplines within the hospice and work together with the guidance of the Cruse organisation. No formal support services such as counselling exists in the hospice for the staff members. A support group for the hospice workers was established during the fieldwork and is discussed in succeeding chapters. Instead a director referred to the 'hospice family'.

In the Day Hospice, varying numbers of patients from the community spend time there. It provides a bridge between their homes and the inpatient unit where they will be admitted eventually. Patients are introduced to the hospice's services such as occupational therapy, physiotherapy, clinical assessment and nursing procedures.

The hospice provides educational services to many disciplines. They include medical students, GP trainees, postgraduate student nurses, community nurses, trainee health visitors, physiotherapists, occupational therapists, home helps, theological students and ministers. The hospice education centre employed one full-time staff member. When programmes were being offered staff members from the hospice contributed towards the instruction of nurses and physicians. A special educational centre had been added to the original hospice complex.

The large Volunteer force of 700 work in many capacities within and outwith the hospice. Some of their tasks include involvement with

patients on the unit, while a great many do not.

Referrals to the hospice are made by the patients' GP or a hospital doctor. The hospice is considered as a symptom relief unit, rather than a long stay unit. Twenty-five per cent of patients are discharged and may then be cared for by the Home Care Service. The average stay on the unit was 15-17 days in 1988-89. Admission diagnoses may include cancer and advanced renal, cardiac, respiratory, neurological or blood diseases.

### **Participant Observation**

The types of participation available to a researcher and the type of participant observation adopted in this study are discussed. Four types of participant observation as discussed by Gold (1958) are: 'Complete participant', 'participant as observer', 'observer as participant' and 'complete observer'. In complete participation researchers are concealed in their role as a participant. Buckingham et al (1976) conducted such a study on terminal care in a Canadian hospital. As the study progressed, Buckingham experienced similar symptoms as did the real terminal patients. In a participant as observer role the researcher forms relationships with participants that enables data collection and the researcher shares most of the participants' experiences (Denzin, 1989). The role of observer as participant is often a one-off event such as an interview.

Spradley (1980) further differentiates between active and passive participation. In active participation the researcher develops



similar skills as the participants. With passive participation the researcher is more a 'bystander' with limited involvement in events.

In participant observation research questions are framed in general terms (Bogdan & Taylor, 1975). The research questions for this study were presented in Chapter 1 (pp. 3, 4).

Participant observation is a role adopted by the researcher as participant observer. Participant observation belongs to field methods where many techniques may be used for gaining information and for interpreting it (Schatzman & Strauss, 1973; Spradley, 1980). Participant observation combines observation, informal interviews and documents as data sources (Denzin, 1989; Spradley, 1980).

Participant observation provides the researcher's viewpoint of those studied. It provides understanding the situated character of interaction. By taking the role of participants, the researcher 're-creates in his own imagination and experience the thoughts and feelings which are in the minds of those he studies' (Bruyn, 1966:12). Participant observation views social processes over time. Bruyn argues that the participant observer seeks to locate meanings that people share through communication. There are no pre-judgments about the nature of the problem. No rigid data-gathering devices or hypotheses are used (Silverman, 1985). In this study a sensitising concept (Blumer, 1969) guided the initial fieldwork. It is discussed later in this chapter.

In participant observation the researcher becomes involved with the object of the study and collects data through field notes. Formal recording of data is sometimes dispensed with. Participant observation is less structured and allows deeper insight into the workings of the setting. It is prone to 'observer effect' or 'reactivity'. This is where the researcher's presence is seen to influence the data (Hammersley & Atkinson, 1983). This can be used to the researcher's advantage when, at a later date, the data is re-introduced to the person. This technique was relied upon in this study. Objective observation involves inference, these involve assumptions (Barker, 1991).

Dingwall (1980) argues that the theorists of ethnography set out general principles of the method but failed to reveal how these principles may be implemented within fieldwork practice (Hammersley & Atkinson, 1983). The result of which are stories telling what the research was 'really like', mostly anecdotal. This is an important and relevant point. It is impossible, in the course of this thesis, to present the details of participant observation in practice, conducted over an eight month period. What I will do is present an illustrative outline of that practice.

#### The researcher's role

I adopted the participant as observer role throughout the fieldwork. My work experience assisted me in adopting this research role for the present study. From that experience I realised that the role of a volunteer nurse would have impeded data collection and recording conversations with patients. That would

have affected my ability to make the extensive field notes on the spot, which I did.

Intentionally I dressed casually on the ward. This decision took into consideration the contrast between the generally well dressed hospice volunteers and the uniforms of the unit staff. However, despite these efforts, I was identified with the establishment by some members of the staff. My name badge stated 'researcher' rather than 'nurse researcher'. Chenitz (1986) argues that by identifying themselves as 'nurse researchers' the implication of a promise to intervene exists. This was the reason for my decision. It freed me to attend to the research duties and was a successful strategy.

Initially routine patient care and staff members' interactions with patients were observed. My informal participation with patients and staff members was sporadic and piecemeal. Practical aspects of activities with patients included: obtaining personal items located in places other than where we were, assisting their drinking fluids, ringing bells or summoning staff in person. With the staff members, I helped move patients and answered the occasional bell. The remainder of time was spent conversing with patients, nursing staff and relatives and observing these people. As the fieldwork developed I was able to ask the unasked questions of participants.

Cassell (1988) argues that 'over-rapport' occurs in fieldwork when the researcher is unable to distance themselves from a group. She suggests submitting to it to learn from informants how things are

done. I followed this strategy at the outset of the fieldwork. However, distance from the data occurs when the formal analysis and writing begin at the close of the fieldwork. Several key informants' deaths affected me. Close relationships had been formed with these patients. I reacted to their deaths on two levels. Firstly, because I had come to know the person. Secondly, their death meant seeking and educating other patients to become key informants. This task became more demanding as the fieldwork progressed.

### Observations

Several issues related to observations in participant observation are considered in this section. Zelditch (1962) recognises the limitations of participant observation. He believes that in no participant observation study is the researcher able to obtain knowledge by their own observations. When phenomena occur sporadically or in the researcher's absence, reconstructed accounts from participants who witnessed the events are necessary to expand the data (Denzin, 1989). The possible effects of the researcher on the participants must be taken into consideration (Hammersley & Atkinson, 1983). Becker (1970) believes that observational reactivity is minimal in field settings because of the multiple events occurring within it, whereas in laboratories it increases.

Observational data in the thesis includes the observations of people and conversations with them. Time sampling occurred throughout the twenty-four hour cycle. Few night shifts were worked because no contact with the patients occurred during those

periods. Observation periods were initially scheduled for approximately eight hours but later modified to a work time of four hours. Short observation periods enabled field notes to be expanded and kept up to date as well as coded. The notes made and used in this study are discussed later in the chapter. Optimal times for conversations with patients were found to be from two o'clock in the afternoon until nine at night and sometimes later. These were times when direct physical care was not usually being given by the nursing staff. Once this was discovered, my observation periods were scheduled around these hours. Observation periods occurred every second day and this gave time for the notes to be expanded and coded. Shifts included weekends and special holidays like Christmas Eve and Day.

At the outset of the fieldwork, comprehension of patients' and staff members' interactions were important. To build a picture of patients' perspectives, observations and conversations with them and staff members was necessary. Early in the fieldwork I monitored the staff members' activities and they were aware of it. Comments like, 'she's watching us', were overheard. Much of the data proved later not to be of great importance. Of course the staff members were also monitoring my interactions with patients.

Because of the unpredictability of death, patients and staff members' retrospective accounts often needed to be relied upon. On those occasions when a death was expected after a shift was due to end, I extended the shift to monitor patients' and staff members' responses.

The classical use of mirrors is noted in complete observation, often through a one-way mirror. Covert observations may be made through windows (Hammersley & Atkinson, 1983). My observations on the unit were aided by the windows and mirrored fire exit doors on the conservatory. They enabled monitoring events and people while sitting in the conservatory and prevented multiple trips into a ward to directly observe an event or patient. When images became unclear or activity changed in wards that I was observing through the window or mirrored doors, I entered them. A key informant acknowledged the same practice but her reason for relying on windows was confinement to a wheelchair.

#### **Study Focus, Sensitising Concept and Research Questions**

Honigman (1970) defines qualitative research problems as discovering what occurs in a setting, their implications and linking relationships between occurrences. Ethnography is flexible and does not entail extensive pre-fieldwork design. Issues are discovered as the study progresses (Spradley, 1980; Hammersley, 1990).

A 'sensitising concept' according to Blumer (1969) provides direction for a study. Sensitising concepts refer to concepts formulated early in a study and they provide lines of investigation (Blumer, 1969). Bruyn (1966) argues that sensitising concepts give a sense of reference or a general orientation rather than a precise definition to a phenomenon under study. These concepts undergo modifications throughout the fieldwork. As the study progresses, sensitising concepts become operational (Denzin, 1989). They may

include procedures or routines as gross features of the structure and processes being examined. For example care that is said to be individualised may be found to be routinised.

'Openness to death' in the hospice was the sensitising concept for this study. It was developed from literature on the hospice movement, the work experience at the hospice and from related research. The underlying research question asked how death and dying are managed on the inpatient unit and what patients had to say about death and dying. The research question developed into how patients perceived dying and deaths and how they, staff members and others described their experiences with these events.

#### Types of events sampled

Different sampling methods enables obtaining information from various events and participants. The researcher explores opportunities for data collection that may be fruitful to the study (Fetterman, 1989). Three types of sampling techniques were used in the study - opportunistic, time and theoretical sampling.

Opportunistic sampling essentially meant making the most of available situations and recording them. Opportunistic sampling included recording events and people according to the information that they are able to provide (Burgess, 1984). Honigman (1970) uses the term opportunistic sampling, while Zelditch (1962) calls it convenience sampling. The researcher's judgment, as to what and whom to observe, is based on the research question. People who were willing to talk to me and offer information related to the

study were sought out. I returned to those people who answered my questions especially about death and dying.

Time sampling involves observing during randomly selected time periods across the twenty-four hour cycle. Hammersley and Atkinson (1983) recommend attempting some time sampling. Time sampling was undertaken for a limited number of night shifts, but because patients were asleep and the unit was quiet these shifts did not produce much data.

Theoretical sampling is selecting observational topics according to emergent themes in the data. It provides direction to what data to collect towards emerging and expanding themes. Theoretical sampling forces the researcher to consider what to observe, when to start and when to stop (Glaser & Strauss, 1967). It allows comparing developing theory between participants and events (Strauss, 1987). Issues which seemed important during the fieldwork were monitored closely. Some issues became unimportant over time. By the completion of the fieldwork the focus was on dying and death related issues.

### **The Patients**

Patients in the inpatient unit were at varying stages of terminal and chronic illness. Their levels of consciousness varied from alert to unconscious states. Some patients were mobile, while others were confined to their beds. Some patients appeared physically ill, others did not. Many patients received palliative care and were discharged and sometimes readmitted to the unit.



Patients died on the unit. One of the practical problems of this study was that deaths did not necessarily coincide with my scheduled shifts. Thus reports from patients and nursing staff assisted with providing information not observed by the fieldworker (Zelditch, 1962). Alert patients provided accounts of these experiences for me. Alert patients were patients who were conscious and aware of their surroundings. They were aware and witnessed the dying and deaths of their room-mates. The alert patients play a prominent role in the succeeding chapters.

#### Assessing the statuses of patients

Assessing the statuses of patients as to whether they were capable of participating in the study was important. The medical and nursing directors agreed to my request to approach patients with information about the study and invite their participation in it. This approach was intended to be unobtrusive, prevent reliance on staff members to select patients for me and save the staff members' time. All patients admitted to the unit during the eight month fieldwork period were potential participants. Since patients' physical and mental states vacillated, criteria were established to assess their conditions. Strategies were used for selecting and inviting patients to participate in the study.

Early in the fieldwork I attended nursing hand-over sessions and interdisciplinary reports to obtain baseline information on patients. Following those reports, I selected patients to approach and speak with. This approach was relied on early in the fieldwork. It was also a means for structuring the initial

observation periods. Attendance at these reports continued throughout the fieldwork, except that later in the study it served another purpose. Because this study was about patients' views on their care and dying and death, no baseline information on patients' medical and nursing care were sought. Attendance at these reports, however, offered that information. Another strategy involved my making a round through the unit and visibly checking on patients' statuses, new admissions, discharges and deaths. This information was collated with information from the nursing and interdisciplinary reports. Another strategy involved daily checks, at the beginning of each shift, of patients' physical and mental statuses. Patients' physical conditions were visibly checked to determine whether they were capable of continued participation in the study. If their physical condition had deteriorated significantly, research issues were not discussed with them, although general conversations occurred. Patients' mental status was assessed by checking whether they remembered events from previous days. The last strategy and perhaps the most important was patients' willingness to participate in the study.

The patient population was unstable because of a high turnover through frequent discharges and deaths.

#### Respondents, informants and key informants

In this section I distinguish between patient participants as respondents, informants or key informants. Respondents answer questions without providing details (Denzin, 1989). They do not offer special information (Fetterman, 1989). Informants provide

information freely while key informants provide detailed information (Denzin, 1989). Key informants became sounding boards for checking out information and interpretations (Fetterman, 1989).

Spradley (1979) argues that key informants can provide detail about an event or scene and that they willingly communicate this information to the researcher. Key informants' biases must be recognised by the researcher according to Schatzman and Strauss (1973). This potential problem of bias in this study was, I believe, in some way partly resolved by the fact that staff members were interviewed on the same issues that patients discussed. Staff members provided another angle from which to interpret the patients' views. Informants also contributed data which is included in the succeeding chapters. Over-reliance on key informants' information may produce an unrepresentative picture of the setting (Fetterman, 1989).

All patients I spoke with initially were respondents. It was what occurred after that which determined whether patients became respondents or informants. Respondents answered general questions, unrelated to the study and some declined participation in it. As the study focused on dying and deaths, not all patients willingly discussed the topics and thus remained respondents. Informants and especially key informants offered information about deaths that occurred, especially those in my absence from the hospice. Informants were those patients who answered my questions about deaths, key informants offered it. Key informants were educated to understand what kind of information I was interested in obtaining. Trust between them and I developed. They were sometimes protective

of the information they provided and did not want staff to overhear our conversations. Some key informants shared their problems and fears with me. Problems often related to their care, while fears pertained to their impending death. Key informants also listened and discussed the tentative interpretations of the data. The data presented in the following chapters consists of information from informants and key informants.

Because not all patients were willing to speak about the dying and deaths, I concentrated on conversing with those that would. This is not to say that the respondents were excluded, because they were not.

#### Information provided to patients in order to solicit their consent

During initial conversations with patients, I informed them about the aim of the study. It was to obtain their views of the hospice. I explained that if they wished to participate in the study, it involved our holding conversations and allowing me to write about those conversations. Patients shared information about the study amongst themselves. This assisted me with the groundwork of introducing the study to other patients.

#### Consent

Conversations, as informal interviews, are common to ethnographic approaches (Fetterman, 1989). These conversations approximate to open-ended questions which enable participants to describe their world. Thus no standard questions are presented to participants.

Instead, they are able to raise issues important to them (Silverman, 1985).

Webb and Webb (1932) aptly define these conversations where 'the investigator must find his own witnesses, induce them to talk and embody the gist of this oral testimony in his sheets of notes' (p:138). This is the method of the interview or 'conversation with a purpose' a unique instrument of the social investigation (p:130). Burgess (1988) argues that ethnographers develop relationships with informants to 'engage in conversation with them' (p:139). I focused conversations on death and dying because not all patients would broach the topic without introduction.

Qualitative research, especially participant observation has 'hidden' or unknown aspects which unfold with the fieldwork and therefore cannot be predicted which makes informed consent problematic (Archbold, 1986). To obtain written consent for conversations with patients was deemed impractical on grounds that not all conversations would be research-related. Signing consent forms may have been difficult for patients confined to beds. This was an unnecessary concern and in retrospect I realise that written consent could have been obtained. However, information sheets left at patients' cubicles may have disturbed relatives who might be upset about the admission. Although the fact that written consent was not sought from patients, I believe that their consent was voluntary and that no ethical principles were breached in the course of the study.

Terminally ill patients are viewed as a vulnerable population that should be protected because of the nature of their illness. This sometimes makes it problematic to make contact with them. Thus in this study patients themselves verbally granted or denied consent to converse with me. If they denied it on one occasion they were sometimes invited to participate another time and some did. Some in fact started conversations later with me even though they were reluctant to participate when first approached. Thus consent from patients was ongoing and repeatedly obtained as we conversed. When special incidents were mentioned I asked them anew whether I could write down their comments. Patients told me when they did not want me writing what they said. This happened on several occasions.

Assurances of anonymity and confidentiality were provided to the patients who consented to participate in the study. It was explained to them that they would not be identified in my thesis.

### **The Staff Members**

Information about the staff members of the hospice inpatient unit and the members of staff who were interviewed are presented in the following sections.

The nursing staff on the inpatient unit included four nursing sisters and one senior nursing sister. Twenty-two staff nurses were employed in full- and part-time positions. There were thirty-two full- and part-time nursing auxiliaries. The nursing auxiliaries undergo a year's theoretical and practical instruction in the hospice.

The way which the study was explained to the nursing staff has already been outlined. The nursing hand-over reports I attended familiarised the staff members with me and vice versa. On other occasions I joined the staff for their tea or meal breaks.

### The staff interviews

Staff interviews were undertaken and this component of fieldwork is introduced by discussing interviewing on a theoretical level. Several authors view the interview as symbolic interaction (Silverman, 1985; Denzin, 1970; Hammersley & Atkinson, 1983). Silverman (1985) believes that the depth of data is obtained by triangulating different sources of data. Denzin (1970) points out that interviews are observational encounters for focused interaction.

Two months before the end of the fieldwork the Nursing Director and I met to discuss arrangements for inviting staff to participate in the interviews. The Nursing Director arranged a meeting at which I presented an update of the study to supervisors of the Volunteer staff and staff members from the unit. The objective of that meeting was to obtain participants for the staff interviews. Even though some hospice Volunteers had agreed to be interviewed they were not approached again since the Nursing Director stipulated that those involved in the interviews must have contact with the patients and many did not. The Nursing Director exercised her power as gatekeeper. Since that meeting I have realised that her decision enabled me to re-evaluate the research plan and decide against interviewing Volunteers. Instead the staff interviews

focused on nursing staff rather than Volunteers whose direct contact with patients was minimal. Few unit staff attended the meeting because the unit was busy that day. Of those two staff members that attended, neither offered to be interviewed.

#### Obtaining interviewees

With the Nursing Director's consultation, another approach for obtaining staff interviewees was taken. Fifteen staff members were approached during scheduled observation periods and asked whether they were interested in being interviewed. All agreed to be interviewed. For personal reasons of the staff members, three arranged interviews were not held. Thus twelve staff members were interviewed. These twelve interviewees had been employed at the hospice from between 6 months to twelve years. Interviewed were 1 Hospice director, 1 junior sister, 3 staff nurses and 7 nursing auxiliaries.

#### The interview settings

Ten interviews were held in a Quiet Room off the unit. They were arranged for before or after the interviewees' work shifts. One interview was held at an interviewee's home. Another was conducted in one of the director's offices.

#### The interview method

The purpose of the interviews was clearly defined. They were intended to confirm or disconfirm the collected data and expand



themes already recognised in the data and possibly create new themes. They also filled in gaps in the study themes from the observations and conversations with patients. Several researchers recognise the merit of this approach. Denzin (1989) argues that during interviews the interviewer must have 'an in-depth working knowledge' of the interviewees (p:118). They must be acquainted with the times and places of interactions of participants' worlds. Interviewers, Denzin argues, must understand the relationships between participants. At the end of the study the researcher offers interpretation that stimulates informants to confirm findings or counter the information (Burgess, 1982). Hammersley (1990) states that interviews may take the form of direct interviewing which seeks to test responses.

Interviews conducted at the end of fieldwork provide data on specific themes and allow the testing of hypotheses (Fetterman, 1989). Structured interviews are beneficial when the fieldworker understands the setting. Structured interviews enable comparing different kinds of data. Close-ended questions assist in confirming data, quantifying and qualifying themes. As Strong (1979) identified, 'what people say depends very much on what questions are asked, who asks them and the general sense of the occasion' (p:226).

A prepared statement about anonymity and confidentiality was read at the outset of each interview to the staff members. This and their verbal consent were recorded on audio-tape. Ten interviews were audio-recorded. Two interviewees declined being taped. Field notes were taken during all twelve interviews. This approach,

however, detracted from the flow of conversation. The advantage of the concurrent note-taking was the ability to observe how limited the information contained in the field notes was, when contrasted with the information available on tape. This observation pertains to the note-taking in general.

The interview questions were formulated from observations and conversational data previously collected on the unit. Structured questions were introduced to the interviewees (See Appendix II). The content and order of questions were modified during interviews, depending on interviewees' responses.

Atkinson (1981) discussed the false security of tape-recorded data. He notes that after transcription, sociological and psychological concepts are assumed to stand out. The researcher assumes that the material speaks for itself. They rush through the analysis and fail to stand back and allow what appears obvious to become problematic or 'anthropologically strange' (Garfinkel, 1967). They may have imposed an interpretive framework and treated the talk as a mere expression of sociological concepts. Strauss (1987) recognises advantages in selective transcription of audio-tapes. Choosing information that pertains to developing categories is wise, rather than transcribing material which will never be used in full.

The main source of data in this study was field notes which were also taken during staff interviews. Three interviews were fully transcribed by hand without mechanical aid. The fully transcribed tapes pertained to several developing themes in the study. The

other audio-tapes were listened to and the field notes were expanded from material on the tapes.

### **Data Records**

In the following sections I discuss the other data records, their content and how they were used in the thesis. The data records discussed here are the field notes, documents and a researcher's diary. The notes made were: field notes, main notes and summary notes. Field notes were made in the field as raw notes. Main notes are the expanded field notes. Summary notes contain analytical and theoretical elements.

#### The field notes

Field notes were the major source of data recording and central to the analysis. In the following sections I discuss where field notes were made, what they contained and how they were integrated into the study. Strong (1979) identified the inaccuracy of field notes because much that is spoken is lost. However, it enabled studying a large number of cases. It does not require the same degree of accuracy in recording like other methods such as conversational analysis. Organisation of field notes is what Fetterman (1989) believes is preliminary analysis which facilitates formal analysis. By keeping the different types of field notes that I did, the observational and analytical notes were separated.

All field notes were handwritten into a 16cm x 10cm notebook. This and a pen I carried in my skirt pocket or in my hand as I moved

about the unit. Observation periods were scheduled to accommodate writing and expanding field notes and their analyses, after each scheduled shift was completed.

The places where field notes were written depended on several factors. One factor was the context of the observed event and whether it was appropriate for making notes. Times when participants were occupied with other activities were optimal for making notes. Hammersley and Atkinson (1983) recommend writing notes as soon as possible after an event and wherever possible are important because recall decreases with lapsed time. Spradley (1980) supports this when he mentions that field notes are to be written as soon as possible after the observational period.

The field notes contained observations and conversations with patients, staff members and others. Notes were made in public and private spaces throughout the inpatient unit and hospice. On the unit notes were made in wards, single rooms, on the conservatory and in the Duty Room. In the cafeteria notes were made on previous interactions. If relatives were being interviewed by me in there, notes were made at that time. The Library became another site for note making. A Research Fellow's office was used when it was vacant. During slow observation periods field notes were decoded from my shorthand and expanded on site, so as to capture as much detail as possible.

There are several forms of writing field notes. They can be written as condensed and summarised accounts or reconstructed. Spradley (1980) identified 'condensed accounts' as verbatim

phrases, words and disjointed sentences spoken by participants. They are valuable because they record accounts verbatim. The inclusion of folk terms capture participants' construction of reality and their perceptions of events (Hammersley & Atkinson, 1983). Verbatim data enables the reader to judge the credibility of the writing (Fetterman, 1989). Summarised statements are more complete than condensed accounts but misrepresent participants because they summarise their accounts (Spradley, 1980). Reconstruction of field notes is necessary when note taking at the scene is inappropriate and should be completed soon after the event (Fetterman, 1989).

An example of verbatim, summarised and condensed notes are provided. The verbatim and summarised accounts are from the same event and illustrate what data is forfeited when field notes are summarised. These extracts are taken from the data.

#### *Verbatim*

- 0     Tabloid laying on table beside Betty.     Headline about Prime Minister Margaret Thatcher axing the NHS. Conversation turns to this.
- B     She gets 'VIP treatment' when she goes to hospital. 'She should get dumped in here. That's what she should get, dumped in here and left'.
- TM    'Do you feel you were dumped in here?'
- 0     She nods head in agreement.
- TM    'What type of place is this to be dumped in?'
- B     'Once you get used to it'.
- TM    'Are you used to it?'

B 'That Sharon shouts at me when she's alone. When Steve's in it's sweetheart and darling. Flowery talk'.

TM 'Who's Steve?'

B 'My son. Steve spoke to Sister. Be gentle to her'. She never 'spoke to her' (0601:2-3).

*Summarised account*

2330. Nurse Bridget showed me back rooms, Sanctuary, trolleys and room where they do bodies, and fridge which holds nine. Card filled on death. Every Wednesday Dr S. Sr and Home Care get together to see how families cope. One year after death card sent, that they're remembered (0226:11-12).

*Condensed accounts*

TM Do you have a good relationship with the Dr?

PT Yes. I yell and 'shout and swear' at him. It's been 3 years, really 4 years. To be told you have a short time is a feeling I can't explain. When they told me I seemed to lose all consciousness. It was like there was 2 of me'. One sitting in front of Dr R. and one behind him by the window. 'Hind quarter', you said you're a nurse.

TM Sounds like a side of beef.

PT Exactly that. Speaks of child. 'He's been the mainstay, you have to have somebody. I don't want the tension in the nurses' way'. The first time I was in every half hour pulling in ...' (0317:10-11).

Wherever possible, I tried to note what was said verbatim. The field notes included the three types of accounts. Condensed accounts, which maintained the verbatim principle, were striven for because of their accuracy but were not always possible. Retaining the verbatim principle had advantages and disadvantages. It captured participants' words and phrases, however, taking notes

while conversing and asking questions was challenging. The disadvantage of writing field notes was that eye contact was broken with participants (see Fetterman, 1989). The note-taking affected the flow and rate of conversations. Some participants assisted me by slowing their speech. When bits of information were missed, I repeated the participant's words and they restated their accounts. Summarised statements were also made but incorporated verbatim words or phrases. Reconstruction of accounts occurred when accounts were reduced to mere verbatim words or phrases. Verbatim data in the thesis are identified by inverted commas. They are followed by bracketed numbers which are references to where specific data is located in my field notes. They can be ignored while reading the succeeding chapters. The discussion turns to how the field notes were expanded and used in the following chapter.

#### The main notes

Field notes were expanded into main notes the same day as the observation period or the next day, when the shift finished late in the evening. The main notes included observations and conversations and are similar to 'substantive notes' (Schatzman & Strauss, 1973). On the right margin of the main notes, two columns were made. One column was for coding and the second for analytical notes. Analytic memos ask preliminary questions of the data (Glaser & Strauss, 1967; Schatzman & Strauss, 1973). The main notes were stored in four flat files.

Analysis is a process of interpretation beginning with techniques like coding (Glaser, 1967) and moving on to interpretation (Glaser

& Strauss, 1967). Codes are named and may be modified throughout the fieldwork period and after it (Glaser & Strauss, 1967). Once the main notes were compiled from the field notes, they were reread and coded, line by line, with codes suggested by the data.

#### The summary notes

Summary notes were written from the main notes after they were reread. These notes are similar to what Glaser and Strauss (1967) term 'theory notes'. They contain preliminary analysis such as theme and hypothesis development and involve making analytic memos (Glaser, 1967; Schatzman & Strauss, 1973). Theoretical notes record conceptual development (Glaser & Strauss, 1967).

Summary notes were made after coding was completed. Rather than focusing on the minutiae of the main notes, the summary notes focused on the development of themes thus they are similar to analytic memos. The summary notes are similar to theoretical notes. They consisted of analytical themes from the main notes. The summary notes are contained in one separate flat file. Later in the fieldwork the main notes were used for writing the summary notes because it was easier to work on one set of notes.

#### The documents

Denzin (1989) argues that documents can be compared with other data sources. Hammersley and Atkinson (1983) identify documents as 'secondary' sources of data. The information documents can provide depends on how they are used and what interpretations are brought



to them. Denzin (1989) notes that documents must be utilised by triangulating them with other data sources. Documents may be used for comparing themes and to develop theoretical explanations (Glaser & Strauss, 1967). Documentary materials have potential uses that are not available from observation (Hammersley & Atkinson, 1983). Secondary records are documents which do not directly relate to particular subjects.

The documents collected in this study, fit into two categories. First there were brochures relevant to the various professionals, such as physicians and nurses, who attended educational programmes at the hospice. The second source of documentation were pamphlets provided for the public's benefit which champion the hospice's mission to the terminally ill, with the reminder that the hospice relies on voluntary funding. These hospice documents were checked against observational and conversational data which pertained to them. They were consulted because a staff interviewee referred to claims made in the documents.

#### The diary

The role of a diary in the fieldwork is now considered. A diary can be a record of the development and evolvement of the research role during fieldwork (Hammersley & Atkinson, 1983; Fetterman, 1989). Hammersley and Atkinson (1983) suggest that a diary captures the researcher's feelings and involvement during the fieldwork. It is a source of data that may be written as preliminary analysis. Fetterman (1989) recommends that diaries be separate from main notes, so that the research role can be examined

more objectively. Denzin (1989) notes that changes in observers are expected. He advises that recording these changes is a way of keeping them in check.

In this study the diary was the basis for monitoring relationships with patients and staff members and changes in them, as well as changes in myself. The diary enabled examining events with the objective of being sensitive to the possible sources of bias. Reflections on my role as a researcher, events during fieldwork and methods are contained in a diary which was kept separate from the field notes.

Deaths posed a methodological and sometimes emotional problem. First, death meant one less participant. The continual recruitment of further participants required educating them about the study. This education of new patients took a considerable amount of time and energy. Educating patients to discuss the topic of dying and death required sensitivity which needed to be meted out to the individual patient. It had to take into consideration the patient's adjustment to the hospice. So, although my objectives were clearly defined, their implementation were only possible when the patient was settled into the hospice and was willing to talk. I noted down thoughts about the challenge of continually seeking participants because of deaths or discharge. The diary also captured my reactions to patients' deaths, especially when they were key informants. The question is whether I was reacting to the loss of the person themselves or the loss of a key informant. Sometimes it was a combination of both.

The diary was most useful during the fieldwork period and then immediately following it. It has no central role in the thesis but served as a basis for monitoring my feelings about some patients' deaths and offered a check on possible sources of bias.

### Multiple data sources

In this section the advantages of multiple data sources are examined. Triangulation, Hammersley (1990) argues, ensures that findings are not 'idiosyncratic' because they are compared with data from other sources. He continues that 'a check on the validity of descriptive claims' is that 'we accept that all kinds of data involve potential threats to validity, and that these may differ in likelihood across data types and sources, then by comparing data carrying different validity threats we may be able to make a more effective assessment of the likely truth of the claim. What is hoped for in triangulation is that the different data sources will confirm one another' (p:84).

The combination of data that he is referring to needs to be more cohesive and not from diverse settings. Triangulation, Silverman believes, has some value, for example when it reveals the existence of public and private accounts of an agency. Denzin (1970) reiterates Silverman's point of cohesion when he argues in favour of methodological triangulation where two or more different research strategies are combined in the study of the same empirical units. '... Through 'triangulation multiple research methods can be used in a variety of settings in order to gain a total picture of some phenomenon' (Hunt, 1991). The test of triangulation for

Bulmer (1977) is in the value of the explanations produced in a particular study.

Silverman also notes that 'observation over time, involving respondents with a range of statuses, is itself a control on hasty conclusions' (Silverman, 1985:20). Triangulation eliminates bias and validates findings by enabling comparison of a number of accounts (Silverman, 1985:105). Bias or a lack of it can be established by assessing alternate accounts.

Two problems with triangulation exist. First, '... we have to be careful about inferring a master reality in terms of which accounts and actions are to be judged. This casts great doubt on the argument that multiple research methods should be employed in a variety of settings in order to gain a total picture of some phenomenon' (Denzin, 1970). Secondly, Silverman recognises an important and practical problem with triangulation. 'Putting the picture together is more problematic than such proponents of triangulation would imply. What goes on in one setting is not a simple corrective to what happens elsewhere - each must be understood in its own terms' (Silverman, 1985:21).

The multiple data sources in this study were used to build a larger picture of the themes. The larger picture of the themes was a multidimensional representation of the theme built from three potential data sources. Thus the themes were filled in and expanded by other data sources. For example data from the staff interviews were used to expand the observation notes. The hospice documents were used to assess claims interviewees stated were made

in the documents.

### **The Analysis**

In the succeeding sections I discuss the formal analysis and emergence and development of themes in the study. The themes are presented as a story. The story is primary and although the analysis may seem secondary it is not. Several authors were referred to during the analysis.

There are problems involved in interpreting qualitative data (Strong, 1979). Strong argues, however, most action is premised on the assumption that a correct interpretation is possible and likely where participants are familiar with events. Bruyn (1966) identified that participant observation apprehends and records the data to illustrate and identify symbolic meanings to the culture being studied. The researcher must describe how they came to understand the meanings studied. They cannot be inferred from observing behaviour. Bogdan and Taylor (1975) identify three problems with the researcher's effects on data. (i) The researcher is like a sieve collecting and analysing non-representative data but is selective in research questions; (ii) the generalisability of findings, are they representative? and (iii) the researcher must be aware of distortions. Analysis, interpretation and writing are part of a process and analysis in ethnography takes on many forms, in many stages, up until the final write up which is part of the analysis (Hammersley & Atkinson, 1983). Analysis, as mentioned earlier, was concurrent with the fieldwork. Four separate weeks within the fieldwork were set aside for analytical integration.

Formal analysis began upon completion of the fieldwork.

Analysis, according to the grounded theory method, requires that the researcher suspend their preconceptions and accept the data for what they are and what is going on. Analysis is a process of moving between induction and deduction and back again. This involves identifying hypothetical relationships and checking them out with further data. This verification process may include modifying or discarding hypotheses (Corbin, 1986A).

The sensitising concept as previously identified, enables the researcher to select concepts and focus on these (Glaser & Strauss, 1967; Denzin, 1989). The sensitising concept can be seen as a guide to conducting the fieldwork. Sensitising concepts operate on two levels, guiding fieldwork and leading to interpretation. Strong (1979) points out that quantifying many aspects of qualitative data is difficult, instead people's typical meanings are recognised. The sensitising concept in this thesis developed into three themes. Patterns in data were sought and their variations and exceptions were noted. Fetterman (1989) identifies that different sources of data enable expanding categories or themes that I refer to. The themes were built from a combination of observational data and other data sources like the patients' comments, staff interviews and hospice documents.

The three themes operate as categories. Categories are produced from coded data which are condensed (Strauss, 1987). They are a conceptualisation of similar incidents, subcategories and the conditions under which these occur. Category development or identification occurs early on in the process, whereas, later on in its development it is strengthened by saturation, where many items of data support the category. Categories need to be examined for similarities and differences and may need to be revised. Data which do not satisfy one category may need to be placed in a separate category (Corbin, 1986A).

Pieces of data from all data sources were placed in the appropriate theme. Fetterman (1989) argues that negative cases of data assist in expanding categories. Negative cases in the data were incorporated into the appropriate theme and enhanced its development. Their inclusion also offers a more representative picture of events and the setting. They provide other sides to the issue being discussed.

The analysis was aided by diagramming concepts throughout the process. Diagrams offer visual representations of an analytical scheme. They represent the categories and their linkages. Diagrams can be useful during the writing stage, when they can provide an outline of the argument (Corbin, 1986B).

#### Thematic arrangement

The themes were developed by writing about them. The three themes are presented as chapters in the thesis. They are: 'concealing



death', 'displaying dying' and 'responding to dying and multiple deaths'. The themes concealing death and displaying dying were initially difficult to distinguish. Death and dying are synonymous with hospices and separating the two was problematic, until it became apparent that dying and death were handled differently.

The chapter titles incorporate participant and researcher terms. Hammersley and Atkinson (1983) recognise how researcher's analytic categories and participants' categories are integrated. Silverman (1985) argues that the researcher's task is to incorporate the researcher and participant categories so that participants understand the account. Formal testing of these categories on terminally ill patients was not possible. The information obtained from key participants was based on the development of a relationship with these patients. During the fieldwork I shared the preliminary analysis with these participants.

Interpretation is anchored in participants' categories (Schatzman & Strauss, 1973). The interpretation melds the coded data and pieces of data together (Glaser, 1978). It links the categories, which in this case are themes (Strauss, 1987). Corbin (1986A) argues that linkages between categories enable moving a category from a lower to higher level of abstraction. As acknowledged earlier, this study remains at a low level of abstraction. The presentation or interpretation of the research is seen as analogous to telling a story. 'For instance, sociological accounts may well depend upon narrative forms similar to those used in ordinary story-telling' (Silverman, 1985:9).



Descriptive accounts are detailed descriptions informed by theoretical schemes. They include the context of events and analysis and are interpretive (Denzin, 1989).

The interpretation is based on the construction of themes and their integration. Construct typologies assist to develop hypotheses and discover themes (Bogdan & Taylor, 1975). I shall discuss the construction of themes first. 'Every human being, symbolic interaction suggests, defines the world differently' (Denzin, 1989:183). Participants' and observer accounts provide multiple perspectives of reality. Together they are linked to construct a theme. Both types of accounts are subjective and confined to the context in which they were constructed. In this thesis I identify the different data sources that contributed to the development of a theme.

As discussed in the previous chapter, ethnography presents 'analytic, thick or theoretical description' (Hammersley, 1990:19). The description melds the hypotheses, interpretations and conclusions into the account as part of the description.

#### Case illustration

The role of case illustrations is discussed because four are presented in the thesis. Case illustrations present data built around a core category (Strauss, 1987). The value of case illustrations are that they enable following through participants or events. The first case introduces the thesis and two other themes. In Chapter 8 three case illustrations are presented which

pertain to the theme of the chapter. These case illustrations introduce both themes and patients and allow the reader to glean a clearer picture of what patients' experienced in the hospice and shadow how the staff managed these situations.

#### Data extraction

Here the identification of speakers in the data extracts and preparation of data for the thesis are discussed. In the thesis speakers are identified by letters in the data extract. The letters correspond with the preceding text where they are identified. Some patients were assigned pseudonyms in the text. For example, Betty in the text, appeared as B in the data extract. If a lady was identified she was referred to as L. Other patients were referred to as P. TM refers to myself.

Participant observation presents many challenges for separating data. The major task involved is extracting items of data from the context of their occurrence, so that they could be presented individually. Thus the result is that some of the data appears to have occurred in isolation. Much like dialogue from interview transcripts. Often the data was part of an ongoing, interactive scene which, however, could not be captured as fully as it happened. The case illustrations depicted several or simultaneous events. The extracts below exemplify this process of extrication. The first data extract below was taken directly from the field notes:

0 (Observation)

Bed 6 is vacant.

TM 'Wednesday there was a lady in that bed'.

0 I point to bed 6.

TM 'Where is she?'

2-3 (bed)

M 'She died. She died this morning. Yesterday morning. You know I can't remember. Died very peacefully at 6 in the a.m. She was an old lady. When that young one went I was upset. She must've gone

0 She points to bed 2.

Friday or Monday'.

TM 'When you said peacefully, were you kept wake?'

M 'No. The nurse said she slipped away peacefully'.

TM 'Did you ask the nurse or did she tell you?'

M 'I asked'.

TM 'Were you aware of what was happening?'

M 'No. Never heard a thing'.

TM 'Did you suspect anything?'

M 'Well we knew she was ill' (0524:2-3).

The next data extract was separated. It begins with a brief summary which sets the context of the scene and accounts for some of the edited data. Summaries are not provided with all data extracts. The data extract was used to highlight the language used in the hospice:

P 'She died. She died this morning. Yesterday morning. You know I can't remember. Died very peacefully at six in the morning'.

TM 'When you say peacefully, were you kept awake?'

P 'No. The nurse said she slipped away peaceful'.

In cases where data extracts were lengthy and repetitious, editing occurred, as it did with ahs, umhs and such.

### **Ethical Issues**

Ethical issues are considered here because as Dingwall (1980) aptly identifies, in ethnography 'there are so many grey moral areas' (p:871). I have identified four major ethical issues which arose in the study and which require discussion.

The first issue involves the consent of patients and staff members to participate in the study. These procedures were explained earlier in this chapter. They are being addressed here in more depth because they are identified as an ethical problem in this study. I wish to begin by reiterating reasons for not obtaining written consent from patients, nor providing information sheets to them.

The reason why patients' written consent was not obtained was because certain patients confined to beds could not provide their signature. In hindsight this was a foolish idea as I indicated earlier in the chapter. It is also the basis for identifying an unethical element to this study. I also discussed obtaining a written consent to hold a conversation with patients. Many conversations with patients were about the weather. Many times conversations were irrelevant to the research. Obtaining written consent for these conversations is less clear-cut. Thus the issue

of written consent is problematic in participant observation studies.

Because dying patients are vulnerable gaining access to speak with them presents an ethical problem. Johnson (1992) addresses the special distinction and dignity which ought to be given dying patients and the ethical issues in participant observation. A case in point in this study was the stipulation, by the Nursing Director, that I could speak with the patients but not tape-record them. I disagree that dying patients should be treated differently than other patients because this different treatment may mean protective measures which the patients themselves might disagree with.

The second issue is also about consent. Staff members did not provide consent to be observed. Instead, blanket consent was provided higher up the hierarchy. Bogdan and Taylor (1975) identify this issue as part of the gaining access 'bargain'. Thus no consent was obtained to observe the staff members.

The third issue is participants' comprehension about the research. Johnson also examined the fact that participants do not understand how the data will be used. On occasions when I provided a detailed explanation about what the study was really about participants did not seem to understand. Bogdan and Taylor (1975) argue that researchers need not elaborate on the substantive issues in great detail. Johnson suggests that obtaining written consent resolves the dilemma. I disagree with him. It would seem that he believes once the consent is obtained the researcher can freely use the

data. He does, however, recognise the impracticality of obtaining consent from each individual where large groups of people are being observed, as does Dingwall (1980). This pertains to the staff members in this study.

The fourth issue involves anonymity and confidentiality. I changed participants' names to maintain anonymity. In the case of some patients, their gender was changed to ensure anonymity. This raises the question at what point does the data become a piece of fiction. Are the examples of data provided typical of the data? Data cannot be typical in the sense that they are context specific and represent a particular perspective. Thus in this sense they cannot be comparable. Rather, they represent common themes in the data. The response is that multiple data sources enabled expansion of themes perhaps unavailable with single data sources.

To me the trust that developed during the encounters with participants was an important indication that I was not violating their privacy. Dingwall (1988) mentions that mutual trust is necessary between the researcher and participants. Furthermore this trust must ensure that the data will represent the setting and participants.

In this chapter I have discussed the actual conduct of field research and its problems. The fieldwork literature suggests it is not a straightforward method, some of the divergences have been pointed out. The rewards of fieldwork are many, such as coming to know participants in a way which is impossible to obtain with some other research methods. It can also be problematic and stressful.

I have pointed to some of these problems. The research topic, dying and death, potentially lends itself to some degree of emotional involvement. Even though this involvement may be a potential source of bias, it is also a reminder of human nature. The researcher is unable to totally disassociate herself from an event that they are part of. Becker (1970) argues that all research is in some way contaminated with the personal sympathies of the researcher. The researcher must empathise and identify with participants to understand them from their perspective yet be detached (Bogdan & Taylor, 1975). It is not my intention to give the impression that the fieldwork was easy nor dwell on its difficulties. It was challenging.

CHAPTER 5

'THEY DON'T TELL THE PATIENTS' : CONCEALING DEATH



## Introduction

The practice of putting terminally ill patients together in wards suggests that death was not to be concealed in this hospice. 'Openness to death' was the sensitising concept which was explored in the study.

The theme as discussed in this chapter - concealing death - suggests that 'openness to death' was not practised in this hospice. The theme evolved from data on the language used in the hospice and refers to death, its discovery and disclosure, and the management of corpses.

I discuss how language, interactions and procedures placed restrictions upon the staff's disclosure of death to patients. I begin with public and private dialogue, which I describe as two forms of language intended for different audiences. Public dialogue was used by everyone whereas private dialogue was restricted to staff members, although some patients used that language to describe their experiences. There follows a discussion of the ways in which patients discovered death. In the last section the management of corpses in wards and on the unit as a whole are discussed.

The argument put forward is that patients were socialised, sensitised and controlled by their encounters with their room-mates' death. Events and language used in the hospice were sometimes arranged by staff as to what patients do or do not witness. This raises the question of whether this management was

psychosocial care or measures to deal with the inevitably difficult issues surrounding death in a ward context.

### **Language in the Hospice : Image and Reality**

Two forms of language were noted to occur in the hospice and certain gestures sometimes accompanied them. Public dialogue was language that was used by everyone in the hospice in all circumstances. Private dialogue was restricted and generally was observed being used amongst the staff members only. On occasion, patients used similar phrases of private dialogue which explicitly conveyed their experiences. It was private and generally was used in private.

#### Public dialogue

Public dialogue in the hospice was learned and shared amongst people. It enabled and socialised people, especially patients and relatives, to converse in a common language about their experiences. Denzin (1987) argues that language is a symbolic production and that it must be recorded as actors create and use it.

Two key words in the public dialogue of hospice staff and patients were found to be 'peace' and 'kind'. Initial conversations with patients and relatives, often included these words or their derivatives. The following data extractions illustrate the contexts in which the staff members used the words.

In the first scene a nurse conveyed news of a patient's death over the telephone saying, 'I'm afraid Malcolm Campbell died this morning with us ... very peaceful ...' (0214:3). The image conveyed to the caller was that of a peaceful death.

Another member of the staff, from the donations appeals department, engaged in public dialogue of this kind while receiving a cheque. Three ladies were gathered around a table in the cafeteria. The staff member said:

S 'Did you find the people caring and understanding?'

One of the ladies mumbled.

S 'Did you find it easy coming back?'

The lady mumbled again.

S 'The atmosphere of the place is quiet and peaceful'  
... 'What a wonderful end for him ... to see the  
money' ... 'Oh, isn't that wonderful ... Gracious'.

They rose and left the room (0729:4-5). A financial donation was made to the hospice in memory of the man they referred to, likely a relative, of either two of the ladies or both, who had been cared for and died in the unit.

The next data extract is taken from a conversation between a patient and myself. I asked her what happened to a room-mate in the ward. She replied:

P 'She died. She died this morning. Yesterday morning. You know I can't remember. Died very peacefully at six in the morning'.

TM 'When you say peacefully, were you kept awake?'

P     'No. The nurse said she slipped away peacefully'  
      (0624:2-3).

This patient accepted that the death was peaceful, from what the nurse told her. Since she was not awake at the time of death, she repeated the nurse's comment.

In the next data extract, staff engage in this public dialogue. During nursing report a nurse announced a patient's condition as:

N     'He really is very poor,. It's just basic nursing  
      care ... just extremely peaceful ... The son's  
      finding it easier now that he's unconscious'  
      (0104:4).

My discussion now turns to other key terms of public dialogue. Hospice staff members are 'kind' and nurses in particular are singled out as 'angels' and 'gems' according to some patients, relatives and staff from other hospice departments. A relative referred to the hospice as a 'kindly place' where 'kindness' prevails (0422:2; 0419:4). A newly admitted patient and I were engaged in an initial conversation:

P     'About your research, if you want to know my opinion  
      about here, excellent. The nurses are gems. They  
      can't do enough' (0518:5).

I asked a patient about her room-mate, whom I knew had died. She said, 'she was ill. She was really ill'. The patient quickly changed the topic (0518:6-7). In this context 'really ill' was associated with dying but using more acceptable words.

In the next scene a nurse was interrupted during report by the telephone. She answered it saying:

N     'When's the last time you saw him? ... He's poorer  
this evening. Your sister's staying the night.  
She's anxious and wouldn't sleep at home' ...  
(0312:1,4).

The nurse later claimed that she told the caller that the patient was dying. This was not straightforward in the language that she used and illustrates how dying was described rather than stated.

Levels of patient's consciousness were also described in relation to their vacillations, for example 'Coming up and going down' (0520:11). Another senior staff member described, via a metaphor, a patient who was previously comatose and expected to die as, 'Marg has come back to the land of the living' (0327:12).

'Away' and 'went' (0608:1) denoted death. In the present tense 'away' was used in conjunction with the discovery of a patient's death, Mr Lee's away (0516:6). When used in the future tense 'away' anticipated a patient's death, 'She'll be away by Christmas' (0409:10).

A gesture accompanied the following communication. I asked a nurse about a patient. She replied, 'Last night at 7.20'. She turned her right thumb to the left and moved it downward (0402:1). Her words, together with the gesture, clearly conveyed the message of the lady's death.

Other phrases of public dialogue were accompanied by characteristic mannerisms. When people such as staff members, volunteers and relatives spoke of the hospice, often they smiled, looked contemplative or expressionless. Sometimes they tilted their head to the side or clasped the palms of their hands together and rested them near their abdomen or elevated them to mid chest, as they tried to find words to convey the meaning of the hospice. These mannerisms become more meaningful when data, later in this and successive chapters, sets the context in which the dialogue and gestures occurred.

In the hospice inpatient unit, in an environment of dying, people may have spoken in vague terms because they were uncomfortable with certain situations that they encountered. Public dialogue socialised people to speak about uncomfortable topics or even ignore them. Others, such as the volunteer working in the coffee room, recited biblical phrases to me. It was her way of expressing experiences she encountered in the hospice.

#### Private dialogue

Private dialogue took the form of private terms that were used to describe patients' deteriorating conditions and deaths. Private dialogue was almost exclusively used amongst staff members. Sometimes, however, distraught patients also engaged in this dialogue. It was not intended to be used in public as some of the terms were descriptive and harsh, in a derogatory way.

A senior nurse referred to a rapid, messy death of a patient as, not a 'straightforward death' (0530:8). Body secretions at the time of death soiled the carpet in the ward which had to be cleaned by shampooing it. That meant temporarily moving patients out of the ward (0527:10). The death was not straightforward because it caused extra work for the nursing and domestic staff.

In the next data extract, the discussion refers to multiple deaths on the unit. Two nurses responded to my comment, you have several spare 'beds since Christmas' by saying:

N1 'We had a clearout last week'.

N2 'One per shift'.

N1 'And then three in the night' (0523:9).

The nurses' statements meant that multiple deaths 'cleared' the unit of patients. Three patients died, one on each of the shifts and three patients' deaths took place during one night. Thus the unit was 'cleared' of six patients.

On another occasion I noticed that certain patients were not on the unit any more and that several were dying and close to death. I asked the nurse in charge what was happening:

N 'It's called the happy hunting grounds'.

TM 'Not all'.

N 'The majority. When they go home, I'll let you know' (0722:1-2).



Her choice of words is classified as private dialogue because it is unlikely that she would repeat the metaphor to patients or their relatives.

Preparing a body after death included several actions which were part of the procedure of 'laying out' the body (0419:12). This term itself is public dialogue whereas the following descriptive terms are private dialogue used within the context of the work of preparing corpses. The body was washed and rectal or vaginal orifices are sometimes 'packed' (0224:10). If secretions persisted, bodies were sometimes 'tipped' to allow drainage (0419:10). By elevating the body or tipping it, secretions were drained by gravity (0224:10; 0731:6). A staff member recounted packing a body without draining it. As relatives viewed the body, the secretions visibly oozed out and soiled the clothing on the body (0224:10).

Patients' engage in private dialogue in wards in the following two scenes. The first patient's husband and grandchild were visiting. The husband moved across the room to patient Pat's bedside to show her his grandchild. His wife shouted out and warned him that 'Pat's half dead' (0315:4).

In another ward, a patient had recently been transferred from a side room into the ward. I asked him about the transfer. Extending his arms in front of himself, palms downward, he moved each hand sideways, indicating a plateau and said, that's it 'flat out, stiffs' (0224:3). Later he became disruptive in the ward and was transferred back into a side room. These moves may have



confused him, if he believed they were indicative of his imminent death.

#### **Patients Discover Death on the Unit**

My fieldwork plan was to explore how patients became informed about deaths, what they were told and by whom. During conversations with patients, I asked them how they learned about deaths on the ward or unit.

Some patients identified a time gap between the occurrence of death and its disclosure by staff members, selective dissemination of information or an absence of it. Moreover, patients pieced together clues and signs preceding and subsequent to death that verified that it was about to, or had occurred. Disparity existed between the view that 'things aren't hidden' from patients and a patient's view that 'they don't tell us about death'. Information about this is now presented, showing that patients did find out about deaths in the unit but without being told openly by the staff.

#### 'Things aren't hidden from them'

'Things aren't hidden from them', claimed a member of the nursing staff (SN6). She implied that patients' deaths were not hidden from other patients. Her view concurred with the study's sensitising concept of an 'openness to death'. Then the following incident occurred. Gentle sounding bells rang twice. I asked a nurse what the bells were for. She said, 'Oh', when 'the funeral

director', and paused before whispering, 'comes for a body' (0126:4). The ringing bell alerted staff members of the undertaker's arrival to collect a corpse at the back entrance of the hospice. The bell could be heard throughout the unit.

Another incident occurred which received a similar response from a nurse. I inquired about the whereabouts of a patient, with whom I had previously made contact and who was now gone from the ward.

TM 'What happened to Beth?'

N 'She died (mouthed silently) this morning' (0715:3).

The whispering and non-verbal mouthing aroused my curiosity about how death was disclosed to patients. These incidents raised questions about whether they were isolated events and whether the sensitising concept, 'openness to death', was upheld. If staff members communicated this information about deaths to me in this way, I wondered how they disclosed the information to the patients. Forthcoming data indicate that this information was intended to be concealed from patients. The incongruity between the staff member's perception that 'nothing is hidden' from patients and the patient's view that death is hidden was apparent. Manning (1984) found in hospitals and nursing homes that staff 'still speak in hushed tones' about death but not in hospices (p:32). Data in this chapter suggested that they did in this hospice.

### The bell

While conversing with a patient in her side room, a bell began ringing. She asked me:

P 'Have you been in the room where they put them?'

TM 'Yes'.

P 'I was in the room by the doors. That's what usually happens. They ring the bell and then take them away. Gives you the creeps. There've been a lot of people that have died in the last fortnight' (0326:9).

This young patient knew that bodies were taken to the back rooms of the unit. During a previous admission she was in a room closer to the doors, which led to the rooms where corpses were laid out and stored. She was aware also that the undertaker rang the bell to collect bodies. Based on the number of times the doorbell rang, she estimated the number of deaths on the unit. Her estimation could be inaccurate though. Undertakers also delivered floral arrangements to the hospice. Also, visitors have been known to be confused by the entrances to the hospice and mistakenly rang the back bell, as I did on my first shift.

### Closed doors

The closing of doors to another young patient's side room assisted her in monitoring deaths. She told me that they've had a lot of deaths on the unit 'in the past month'. She could not have known about these deaths because she had not been admitted to the unit that long. I asked her:

TM 'Have you been in that long?'

P 'No. The nurse told me. They had two deaths. The nurse asked to close my door while they brought the beds by and I knew there were deaths' (0530:6-7).

The staff member offered the information about the deaths. This patient learned to associate closing the door to her room with death. This procedure is discussed further, later in the chapter, under the section 'Corpse Removals from the Wards'.

### The nod

An elderly patient in a ward was not told about her room-mate's death. She interpreted a nurse's behaviour, however, as indicative that the room-mate had died. The patient and I were conversing. I noticed a new patient in the ward and asked what had happened to the lady who previously occupied the bed:

P 'She died. They never told us. I looked over at the nurse and she nodded, so I thought she died. That's what they do. They don't tell the patients. I suspected that was happening. The family was coming in late at night. We weren't told officially'.

TM 'How do you feel about not officially being told, when one of your room-mates die?'

P 'Well I don't know how I feel. As I say no words were spoken, but I knew what happened' (0518:1-2).

This patient associated the nurse's nod and late night visits from the family with her room-mate's death. The informant was an elderly lady who claimed that staff do not tell the patients about deaths. Disclosure about death seemed inconsistently and selectively communicated to patients. Information about deaths was

not always provided to all patients in the same way. Younger patients, data suggested, seemed better informed about deaths on the unit.

Taking 'the whole bed out'

Suspicious behaviour by the nursing sister in a ward provided the basis for the next patient confirming her room-mate's death. Later on she was told about it. The patient discussed her thoughts about the Sister's conduct:

P ... 'I was told'.

TM 'By whom?'

P 'One of the staff. No names' ...

TM 'Did you suspect that the lady was dying?'

P 'Yes. That might, this sounds a bit odd, there was a kerfuffle. Loud noises, and then Sister came in and took the whole bed out. Then I knew'.

TM 'Did they tell you then?'

P 'No. No' (0525:7-8).

The death occurred during the night and this patient heard loud noises in the ward. She observed Sister moving the bed with the body on it. The priority for the Sister seemed to be the corpse. Presumably the staff believed that patients slept through 'loud noises and kerfuffle' in wards. However, the patient became informed about the death by collateral events.

### Empty beds at daybreak

Without communication from staff members about the disappearance of two patients from a ward, another patient discussed the sign she interpreted as indicative of their deaths. This patient was a key informant who knew that my vague opening remark pertained to deaths, thus her quick and focused response:

TM 'It must be confusing, you never know when people come or go'.

P 'Those two people at the top died. Nobody said a word'.

TM 'How did you know?'

P 'When the bed was empty in the morning, but nobody said' (0601:3).

This patient awoke to empty beds and associated them with patients' deaths. Since patients also were transferred between rooms on the unit, it was possible that those she referred to in the above extract did not die but were transferred elsewhere. Patients were sometimes confused about room-mates' movements about the unit. Still, patients near death were often moved to side rooms prior to their death. In which case my informant would have been correct.

### Nothing happened

Death occurred in the cubicle directly across from the patient I talked to in the following extract. The death happened during the night and she witnessed some of the events. She listened to the conversation between a doctor and nurse. I began by summarising, to the patient, the information she provided me with:

TM '... You told me the lady across the way died and the doctor said to the nurse, did you see anything? and she said everything. Did the nurse speak with you?'

The patient shook her head to indicate no. Earlier she stated that the doctor had checked with the nurse whether she, the informant, witnessed the death. The nurse claimed she had. I asked the patient whether the nurse then spoke with her and she, the informant, claimed that the nurse had not.

P 'No. They were about to see me. I was behind the curtains. I listen to their conversation. Even when you're dead they're on about your bowels. If not it'll rise and burst and then you'll have a mess to clean up. The doctor finished and turned around and said, do you think she saw anything? That was me. The nurse said, she saw everything' (0601:3-4).

Screening of bodies may occur before or after death. This point is discussed later in the chapter. Bowel care is a priority in the hospice according to this patient. She believed it continued to be so even after death, since the doctor and nurse were discussing the status of the corpse's bowel.

TM 'Did you know the lady was dying?'

P 'She had four daughters and a son, and one of them said she won't last long. The night she died they were in a terrible state' (0525:10-11).

The family gathering and their conversations suggested the gravity of the patient's condition. They provided collateral evidence, which the informant later used to establish the patient's death because the doctor and nurse's behaviour suggested that nothing had happened.

Data presented in the sections of this chapter thus far, indicates various means by which patients discover or are informed about death on the unit or in their wards. Patients availed themselves of non-verbal staff behaviours and collateral events for establishing what happened to their room-mates. It was clear that patients did not find out about deaths through the 'openness' of staff.

My discussion now changes focus from the patients to the staff members and their different perspectives on the management of corpse removals from the wards.

### **Corpse Removals from the Wards**

Members of the unit staff and other hospice personnel undertook elaborate procedures when moving corpses from wards to the mortuary. Corpse removals were intended to ensure minimal disruption on the unit. Disorder during corpse removals occurred when unexpected events happened or people were encountered along the route to the back rooms. In the following sections, the procedure of preparing corpses for the removal are discussed.

#### The procedure

Under ideal conditions, the staff interviewees claimed corpse removals were straightforward procedure. The data extractions below are taken from their interviews. They outline the steps in transferring corpses and informing ward patients of their intent to do so.



'If a patient dies in the ward, the curtain would immediately be pulled around the bed' (NA4).

'Well, we move them immediately when the patient dies' (NA24).

'First of all, the others get told' of 'the death. Usually what I do, I quietly go round to each one' of them in 'the ward and just explain that the patient has died and try and give the distressed, try and sit and give some comfort while maybe one of the other nurses take over' (NA1).

'Tell the other patients that the patient died' and we're going to move the patient (SN6).

TM 'Do you always tell the patients?'

'I'd say yes, but there are sometimes exceptions'. We had a man who saw a large number of deaths and he told us he didn't want to be told. 'It distressed him. He didn't like the curtains drawn', when we moved the patient (SN6).

If the other patients are with it, they are informed and asked 'if they want their curtains drawn' (NA4).

Do they want their screens pulled round them or screens left. 'They have the choice', or it's put in a way they don't' (SN7).

Tell them they were 'very poor' and move them 'immediately' and return the bed (NA24).

The extracts above are amalgamated to illustrate the variance in the accounts. One interviewee stated that room-mates were told about deaths in their wards. Another claimed that assessments were made to determine whether patients and which ones were to be informed about the death or whether to close their screens during removal of the body. Public dialogue was noted to convey the condition of the deceased, preceding their death. For example that they were 'very poor'.

Corpses were not always removed immediately after death. Situations were assessed, such as whether people were in wards or visiting hours and meal or medication times were underway. Such

events could influence when the transfers were carried out.

The information provided by the staff interviewees identified the ideal step by step approach in removing corpses. The interviewees took note of any anxiety that might be caused by the removal or any unexpected encounters that might interfere with the procedure.

Corpse transfers, I argue, were problematic in themselves, especially when people witnessed them. Alert room-mates in wards posed the first problem. Moving corpses outwith the ward, without the room-mates witnessing it, was the first manoeuvre which was sometimes problematic. These alert patients were important to consider because of the multiple dying and deaths they may have witnessed during their admissions which are discussed in Chapter 7.

Other particular elements of the corpse removal procedure are now discussed.

#### Concealing the corpse

Cubicles were screened after death and concealed corpses within them, as illustrated in the extract in the next sub-section. The philosophy of the hospice movement espoused leaving corpses within public view. Other hospice inpatient facilities refrained from drawing screens around cubicles at the time of death, according to Abel (1986). In a guide on hospice care, Buckingham (1976) outlined patient care where, when someone died, curtains were not closed around the beds. Screened cubicles enabled the staff members to control who witnessed the death. Their efforts could be

understood to be protective and controlling. They were to prevent distress that a death might give rise to. The manoeuvre could also benefit the staff, who might be anxious when corpses remained in wards. Extra measures, such as those described in the following section, ensured that the screens concealing a corpse were secure.

#### The clothes pin

In this scene the data were extracted from observational notes that suggests that staff members were uncomfortable with a corpse behind screens.

Death occurred in a ward which I was observing, next to the cubicle (3) where a patient and I were talking. Whispers were overheard coming from behind that screened cubicle (2). A nurse appeared from behind the screens and walked over to the patient in bed 4. She said to her, 'Muriel, Sally's just died. I feel low'.

I was disappointed that I missed observing the preceding events in the ward. However, I was engaged in conversation with another patient and facing away from Sally's cubicle. As our conversation finished, I went behind the screened cubicle to confirm the death. As I left the screened cubicle, I noticed the nurse was gone from the ward and that a clothes pin was clipped on the screens.

The cubicle containing the body continued to receive much attention from the staff coming into the ward and observing it or going behind the screens. This seemed illogical, given that the corpse was going nowhere until the staff decided that it did.

Alternatively they may have been satisfying their curiosity about the death, as I had, or part of their emotional leave taking. I continued to monitor the cubicle. Later, another nurse entered the ward. She immediately headed for that screened cubicle and drew the screens closer together. Although the clothes pin was still in place, the screens had been left open slightly by visitors visiting the cubicle (0313:6-11).

#### Sealing the unit

In this section I discuss the procedure when corpses were moved through the unit. The main corridor was the pathway for corpse transfers to the back rooms. During these transfers, the unit was externally sealed to restrict public access to it and sealed internally to impede movement within. Thus the intention was that patients and visitors were prevented from observing corpse removals through the unit. The distance the removals travelled, depended on which room they originated from. For example, the distance from ward 1 to the back rooms was further than from ward 4 and involved greater attention to internally sealing the unit because the former transfer took longer. The further the distance, the greater the potential for people witnessing it.

The following data extracts are staff interviewees discussing the measures undertaken to secure the unit, during corpse transfers, from within and outwith:

'We close all the doors when we're taking them away and don't let anyone into' the 'nursing wing' (NA24).

'All the ward doors and single rooms are closed while we move down the lane' (NA4).

'We inform the receptionist that we're going to do that' (NA1).

'She's not to let anyone down the corridor' (NA29).

'She holds back any visitors'. So they won't let 'anybody' in (SN6).

'Then we tell reception okay' (SN7).

Doors to wards and side rooms on the nursing wing or unit were closed, as were the main doors to the unit. Corpse removals passed by these closed doors. These measures restricted patients' and visitors' movement about the unit for the brief period that the transfer took. Receptionists located outside the main doors to the unit were supposed to externally seal the unit to entry by the public.

The procedure was such that visitors checked in at the reception desk upon arrival at the hospice and before entering the unit. The receptionists were provided with updated written information on the status of patients and referred to the update when visitors consulted them. This procedure prevented distressing or embarrassing situations like, for example, visitors arriving to find the patient they intended to visit had died.

By detaining visitors, the receptionists were involved in removals of corpses. Staff interviewees claimed the removals were straightforward procedures. However, if the number of people on the unit was high, especially during visiting hours, I wondered how simple diverting patients and visitors from witnessing the corpse transfer was. Forthcoming observational data suggests that corpse

removals could be problematic. One such case is presented later in the chapter.

Removal procedure for whose benefit?

The staff interviewees were asked whether corpse removals were a straightforward procedure and whom they were intended to safeguard. Their responses differed as to whether patients or visitors were being protected from witnessing the corpse removal. In the first data extract the interviewee claims corpse removals are not a straightforward procedure but are for the benefit of patients:

'But it's not. Whipping the patient in and out of the room'. Some patients we tell to wait inside until we move the body (SN7).

She described a situation where patients entered the main corridor and may have witnessed the corpse being moved. The staff members responded by 'whipping' patients back into their rooms until the body had been moved down the corridor to the mortuary. The irony was that patients likely saw the corpse but the removal procedure was still followed.

The next interviewee suggested other factors and people requiring consideration when transferring the bodies:

'At tea time you've got to be careful there isn't visitors coming up and down the corridor'. It's 'really the visitors, otherwise it's straightforward, wheeling the bed out' (NA10).

She was mindful of regularities like tea time, when visitors might be on the unit. Her colleague, in the following data extract, recognised that patients were aware of what was happening:

'And I say the long-term patients have got to know the routine of, of closing doors. What it means. I'm sure they have. And the drawing of, well screens, We usually mention that the patient has died' (NA1).

Her view concurred with data earlier in the section 'Closed doors', where a patient estimated deaths by the number of times her door was closed. This interviewee was aware that patients knew that closed doors and drawn screens meant death. Her response suggested that patients were usually, but not always, told about death.

In Wright's (1981) study, body preparation was done at night so that room-mates were not upset by the body. Deaths which occurred during the daytime were left until the night shift. The body was also concealed by the curtain. The delay in preparation prevented patients and others from seeing it. The concealment spared patients from witnessing the corpse. Despite the intended concealment, when the corpse removal occurred, whether day or night, patients noticed it. Wright did not specify whether other patients' screens were drawn during it, but I assume that they were not. The closing of screens could have awakened patients. However, if screens were closed they would have ensured that the removal was not witnessed.

The corpse removal procedure in disarray

This section follows the case of 'Abbey : In the Final Acts'. The data are observational and illustrate the disorder on the unit during the removal of Abbey's body because of a communication breakdown. The data illustrate that the corpse removal was the primary nursing task and that communication about it with patients was a secondary task.

Abbey's body had been behind screens in the ward for over an hour and a half and was about to be moved. I was monitoring her cubicle (1). At the time I was on the conservatory, just outside the ward.

Nurse Karen entered the ward and darted behind the contained cubicle. I suspected she was preparing to move the body. Karen reappeared from the screened cubicle and promptly went over to patient Doris' cubicle (6) and closed her screens, without saying anything or looking at her. Auxiliary Edith entered the ward and joined Karen. Two other staff members opened the curtains of cubicle 2 and left the ward with a commode. Karen then walked toward patient Elspeth's cubicle (4) and hastily pulled the curtains. Again, without exchanging words with her. Elspeth was aware of the death, as previously we had discussed it. None of the staff had spoken to her about it.

Karen returned to the contained cubicle and joined Edith who was opening the screens to clear the way for the bed with Abbey's body on it. Hurriedly they pushed and pulled the bed to the open ward doorway, just as visitors walked down the main corridor.



My vision was restricted from the conservatory, so I joined them at the doorway. I assisted by holding the cubicle screens that Edith was entangled in. 'That's the second time', she said. Her face was red and she appeared upset. In raised voice she told me, 'The lady at the desk keeps letting them in'.

Karen then left the ward, closing the door behind her. She returned shortly and told us, 'She's red-faced'. She referred to the hospice volunteer at the reception desk, who let the visitors into the unit. This was likely why Edith was flustered. Presumably the receptionist had allowed people to enter the unit twice and they may have seen the body. 'Do you phone her?' I asked. 'No we tell her', replied Karen.

Hastily they pushed and pulled the bed again. The quick movement caught the foot of the bed on the doorjamb, angling it so that further motion was restricted. Shifting the bed about, they freed it and speedily, almost running, rolled it down the main corridor to the open doors at the end of the corridor and into the back rooms.

I followed the procession and noticed that the doors to rooms occupied by patients, both wards and single rooms, were closed. Not a single person was in the main hallway (0615:8-17).

The object of corpse removals was to prevent patients and visitors from witnessing the corpse. Although the staff members lost control of preventing visitors from witnessing the corpse, because the unit was improperly sealed, they succeeded in preventing

patients in the ward from seeing the body and no or limited communication about the death took place. The scene in 'the corpse removal procedure in disarray' represented the primary task of body removal, separate, at least temporarily, from the secondary task of communication about the death.

## Discussion

Death concealment is analysed in this discussion through two topics: communication forms and support versus control. The routine nursing work, I argue, was managed in the hospice to minimise emotional upset about death and assist in maintaining order. Order was essential to prevent disruption when death occurred. Measures were taken by the staff members to conceal death from patients and their visitors. Thus a continuum of socialisation to death, on the one hand, and social control to maintain order through death concealment, on the other, was evident. People were socialised to interact amidst the dying patients in the hospice by, for example, using the public dialogue terms and engaging in modelled behaviour. The socialisation ended when death occurred. Then social control began because death was intended to be concealed from public view. Thus the socialisation to death was only selective. At the point at which death potentially threatened emotions and order on the unit, control superseded it.

Minimising emotional upset and maintaining order on the hospice unit was apparent in: language, which included public and private dialogue - which included disclosure of information about deaths by

the staff members and secondly, the strategies engaged in managing corpses. The discussion focuses on these two elements. I will discuss language first.

#### Forms of communication

Communication about death in this hospice appeared to be selective, delayed, evasive or absent. In this chapter the incongruity between the staff member's perception that 'nothing is hidden' from the patients and the patients' view that death was hidden was apparent. Data in this chapter revealed that some staff spoke in hushed tones about death. This discussion explores why that may be so.

Public and private dialogue were two communication forms in the hospice. Public dialogue was common currency in the hospice and was learned and shared by everyone, whereas phrases of private dialogue were restricted to staff members and some patients. Data have been presented which underpin this analysis. Bruyn (1966) argues that the observer is interested in the role that language plays in forming meanings under study. He stated that language influences the observer such as using the language that is used in the research site.

Terms of public dialogue such as 'peaceful' and 'kind' were the result of the socialisation process in the hospice. People assimilated the terminology into their vocabulary and maintained the decorum that seemed appropriate behaviour in a hospice. Sites (1973) pointed out that interacting people require a language and

that it is a subtle form of social control. Thus they engage in the language that was used in their presence, although it may be atypical for them. Sites calls this 'acceptance behaviour' which occurs when people voluntarily or involuntarily join groups. People sometimes willingly submit themselves to control by the behaviour they engage in (Cumming, 1968). Sites (1973) identified that some groups have vested interests in perpetuating language and behaviour. Staff members subtly instilled the message that the hospice was a peaceful place even if it was not always. Patients and relatives learned the language and behaviour which helped them function in a new environment. The dialogue and hospice ethos benefited those who were initially anxious about the place.

In a study of medical clinics, Strong (1979) suggested looking for the inherent dichotomies and for overt and covert elements in language and encounters. Strong noted differences in what is said in private and public as did Cumming (1968). Strong suggested looking at the ceremonial order of an event and looking for variance between superficial and substantial elements as participants perceived it. The impression was given that death was overtly managed, yet, language and staff members' behaviour contradicted this ideal. The whispering about death was one contradiction. The data showed that death was attempted to be concealed from the patients.

Strong's comparison is similar to what Goffman (19659) calls 'frontstage' and 'backstage language'. Frontstage language is intended for everyone. Backstage language may be profane or abbreviated and is not intended for the general audience. Public

dialogue corresponds with frontstage language and private dialogue with backstage language. This notion of frontstage and backstage will be discussed in Chapter 8. Public dialogue represented hospice image versus reality, with private dialogue incorporating the cruder aspects of hospice work. Silverman (1970) argues for the necessity of organisations obtaining a market for presenting an image to the public. That meant portraying an acceptable image of the hospice.

Amongst staff interviewees, some acknowledged that corpse removals were intended to prevent people from observing death. They suggested that communication with ward patients about death of room-mates and removal of bodies was priority. However, in practice, the communication was piecemeal, delayed or absent. However, since concealment of bodies was acknowledged, perhaps the oversight was not an exception. Nevertheless, patients discovered death through alternate sources of information. Thoreen (1983) advocates that death should not be hidden when it occurs and that patients are told about it, as do O'Brien and Monroe (1990).

Communication that is socially controlled, Sites (1973) argues, includes the following: 'withholding information', hiding facts and avoidance. Avoidance he defines as when people do not confront something which is threatening. In the hospice, death appeared to threaten emotions and order on the unit. What Sites described was found in the following studies on patients dying in hospitals, Glaser and Strauss (1964), Sudnow (1967) and May (1991) found differences in the dissemination of information, as did Kubler-Ross (1969, 1975) and McIntosh (1977). What was told to patients and

how it was told varied in these studies. In this study data illustrated that younger patients tended to receive different and more information about deaths which elderly patients sometimes did not, as did the above authors. In hospitals, Dunlop and Hockley (1990) noted from their experience in wards with terminally ill patients that they were not told of the death of another patient. They were left to guess their whereabouts or given an alternative story. In this hospice as well, patients were not always told about room-mates' deaths. As far as I am aware, patients were never given an alternative story. As will be shown in the next chapter, patients were also transferred about the unit, thus disappearances of patients were speculated about.

Deaths in the hospice occurred frequently. Despite this frequency it still seemed to cause uneasiness in the staff. Perhaps this is why they tried to normalise it through limited or delayed disclosure and routine work strategies. They may have been anxious about death, both for themselves as well as for the patients.

#### Support versus control

Being supportive and controlling require different skills (Cumming, 1968). Thus with corpse removals, the objective of the controlling task was to remove the corpse. Speaking to other patients before the move could have provided support for patients. However, it would have interfered with and delayed the corpse removal. Also the staff may have been nervous about the procedure itself and only able to focus on one task at a time. Staff members might have been disturbed if the corpse removal was in any way interfered with.

Cumming noted that tension between support and control measures are common in agencies. This explains the tension of corpse removals.

Wright (1981) observed that despite procedures for removing bodies, inevitably patients observed it. In his study nurses approached the patient, listened to their questions, answered them and remained with them if necessary. Sudnow (1967) noted that despite routines for managing corpses, they sometimes failed and led to the discovery of death. Procedural blunders caused disorder and in the case of 'the corpse removal procedure in disarray', exposed the corpse to public view.

Various aspects of death in the hospice were concealed. They included, as described: the undertaker's collection of bodies, moving corpses from the unit by closing doors and whispering announcements about death. Although these events happened, staff members were reluctant to acknowledge their practice. I witnessed staff members' sealing the unit in order to transfer corpses. Their reluctance perhaps suggests their discomfort with death and the procedure. By controlling what patients did or did not witness, the staff may have believed that they were supporting patients from events which may have disturbed them.

Communication about death that was shared or withheld from patients maintained control. This is a subtle social control process that begins by socialisation that then becomes control but was not always supportive. People were socialised as to what could and could not be discussed. The latter of which was control. Because of the uncertainties in hospice care, relatives and patients were

vulnerable and susceptible to subtle control through the information they were or were not given. For those patients who were not told of death, they many times pieced together the clues and arrived at a similar conclusion.

This chapter revealed that death seemed to be concealed from the patients in the hospice and how it was achieved. It was achieved through language, communication about death and nursing procedures, such as corpse removals. Order seemed to be established through death concealment and by withholding information about deaths, from some of the patients. The patients, however, learned about death through various sorts of information. Death work - like corpse removals - was routine work. Death was as private as the routines accompanying it. Student nurses in Melia's (1981) study recognised the importance of routines, which were applied to many work tasks. The nurses May (1991) interviewed viewed death work as routine. These two studies suggest that death work is one aspect of the various work routines. Death work has no special status in the sphere of work, except that it was priority over communication about death with room-mates. This point seems antithesis to hospice care - where corpses are priority to patients. In the next chapter the management of dying is explored.



CHAPTER 6

SEEING 'WHAT DEATH IS LIKE' : DISPLAYING DYING

## Introduction

The previous chapter described the management of death in the hospice inpatient unit and showed that, contrary to the proclaimed ethos of the hospice, death was concealed. In this chapter I discuss the management of dying.

The hospice was designed for communal care, thus the majority of beds in the inpatient unit were in wards. In this hospice a total of twenty-four of the thirty beds were in wards, the remainder being in single rooms. Patients with varying terminal and chronic disease conditions, ranging from alert to unconscious states, were put together in wards of six beds each.

The incongruence in the chapter title, 'displaying dying', is intended to convey an analytical point. A patient's relative was told by a doctor that patients were nursed in wards to 'see what death is like'. However, the last chapter revealed that death was concealed, thus it was dying that the patients observed rather than death. Terminal situations were managed in such a way that death, whenever possible, was not witnessed. Dying, on the other hand, was displayed in the wards.

I argue that situations could be problematic where dying was occurring in wards and that dying influenced the atmosphere in wards. During death vigils, when people were awaiting death, some relatives disliked the openness of the ward and desired the privacy that side rooms offered. Side rooms alleviated stressful situations on the unit that affected other patients. Transferring

patients between rooms, from wards to single rooms, resolved some problematic situations. Because side rooms were limited in number, they were not always available and so the majority of dying patients were nursed in wards. This was not necessarily by their choice.

This chapter exposes the problems with communal ward care because most patients die in open wards. It illustrates the differences between peaceful and problematic dying and how they were managed. It also examines the lack of privacy for relatives of patients dying in wards. Staff managed patients so as other ward room-mates and visitors would or would not see certain events. This was assisted by how single rooms were used.

### **Induction into the Hospice**

Induction into the hospice began as soon as people entered the facility. In this section the influence of hospice ethos, the decor and language that were discussed in the previous chapter are introduced and drawn upon. People, whether patients or relatives, could face uncertainties in the hospice. If they were newcomers to the hospice, or were unfamiliar with care on the unit, they might question what happened and what they might observe.

Newcomers to the hospice often commented on the decor soon after their arrival. The hospice was tastefully decorated in pastel shades with furniture that surpassed the functional pieces often found in NHS hospitals. The floral arrangements that were placed throughout the building were the basis for many conversations with

patients and others. An Italian doctor, on an educational course, mentioned the hospice cat often seen prowling about or curled up on a chair. He seemed taken with it. Patients spoke about the peaceful atmosphere in the hospice. These comments and conversations were part of the public dialogue which was discussed in Chapter 5.

Goffman (1959) points out that decorations and fixtures 'tend to fix a kind of spell' and influence behaviour. The decor in the hospice sets the scene. People accustomed to hospital decor were often taken with the homely hospice decor. Their comments became a topic of conversation which temporarily suspended their uncertainties about the dying that they witnessed.

Appropriate behaviour in the presence of dying patients was modelled by the staff and was also observed in relatives and patients who were familiar with the hospice environment. Later in the chapter and in the next, I will discuss the effects of dying on others. The sensitisation to dying, I argue, was partially sustained by the hospice decor and language used in the hospice.

Sensitisation and desensitisation, Zimbardo and Ebbesen (1969) argue, is an element of social control. Social control and collective behaviour are processes which relate to similar phenomena, Turner (1967) notes. Social control is part of collective behaviour which relates to the process of socialisation. Turner continues that social control implies collaboration that is influenced through interaction and by common objectives.

The hospice decor, modelled behaviour and language introduced, sensitised and desensitised newcomers to the hospice and what they were about to see in it. This may have allayed some of the anxiety that they felt. It also became the basis for subtle social control by the staff. It may have influenced or prevented discomfort by newcomers or their being alarmed by the sight of dying patients. Induction into the hospice was helpful for visitors and staff members. For visitors it was an introduction to appropriate behaviour and language to be used in the presence of dying patients.

#### **Public Dying in Wards**

Patients at varying stages of terminal illness or chronic disease conditions shared wards. Thus alert dying patients could be amongst other patients who were nearer death and who could even be comatose. Comatose states vacillated. Restful coma may suggest sleep. Restless coma may be accompanied by respiratory changes that created noise in wards. Cheyne-stoking respirations, common as death approaches, are rapid, shallow breathing followed by periods of apnoea and often accompanied by loud noises.

Data in this section illustrate the mix of patients in wards. Dying patients were in view and could be observed by their room-mates. All who entered the wards witnessed these patients too. The following data illustrate how dying patients may or may not influence the atmosphere in wards, ongoing activities within it or the individual patient experiences.

The dying patients

In the first data extract taken from observational notes, ward patients appear oblivious to their room-mate's unconsciousness:

It is breakfast time. The patient Hannah is laying on her right side in bed. Her body is still and she is breathing quietly. Her facial colouration is greyish. Several staff members are scurrying about, assisting the other ladies with their meals and producing wash basins, as morning care follows breakfast. None of the staff approach her cubicle (0130:1).

Hannah is restfully comatose. The staff therefore can concentrate on the other patients' care. The open screens at Hannah's cubicle enabled the staff to monitor her condition while undertaking other tasks and for her room-mates to observe her.

Another scene suggests that Bonnie, an alert patient, is aware of the patient directly across from her cubicle. This lady is comatose in bed. Bonnie is bedridden and her physical condition is deteriorating. She is unable to leave the ward without assistance. Bonnie appears tired and a bit down in spirits today. We are talking as she awaits supper. The following is what Bonnie sees and hears:

The lady is on her back and her respirations are noisy and congested. The sound of her breathing is heard in the ward. As she inhales and then exhales, her head slowly bobs up and down. Her face is greyish-yellow coloured and waxy looking. Her eyelids are partially open; revealing eyeballs which are rolled backwards. Bonnie notices me watching the lady and glances over at her for a brief moment. She looks as though she is about to cry. Asking if she is feeling low today, I touch her forearm. She tells me that, in the night, 'I

had a pain in my tummy' (0326:11).

Bonnie said nothing about the woman across from her. The combination of breath sounds and the jerking of the lady's head drew attention to her, unlike Hannah, in the previous data extract, who was restful. I believe that Bonnie was compelled to witness the sight and sounds of the lady because Bonnie was confined to bed in the ward.

In another scene the patient was in a ward and drew attention to herself because of her body position:

The patient is in bed (1) and her neck is twisted to the left, angling her face upward and back towards the rear wall. Her face is pinkish white, with slight jaundicing and her eyelids are open, exposing fixed eyeballs. Two ladies are with her and one of the lady's eyes suggests that she had been crying. They are glassy. The women are alone at the cubicle (0805:1-2).

The patient was conspicuous, even at a distance, because of her body position, facial discolouration and fixed eyeballs. People entering the ward from the main corridor would pass by her bed because her cubicle was next to the door. The scene above occurred during visiting hours and visitors and patients were present in the ward. No one spoke with the two ladies.

During the work experience a staff member stated that when death was imminent, patients were left alone. She referred to a comatose patient in a ward without anyone at her bedside. Thus it would appear that staff do not sit with dying patients. This point is addressed at length in Chapter 7.

The similarity between dying patients and corpses can be seen in the following. Becker and Bruner (1931) cite unpleasant attributes of corpses. These are similar to characteristics of some dying patients in the hospice wards. They list facial expressions and colour, partially opened eyes and body postures. They identify people's discomfort which is generated by visual and other stimuli accompanying the illness and approaching death. People's natural impulse is to withdraw from the sight of dying patients as this causes an affective response and the emotion of fear. Despite such stimuli in hospice wards, people behave as if they were dealing with 'normal' situations. Turner (1967) notes how appropriate behaviour occurs:

Instead of acting simply and naturally, as a child, responding to each natural impulse as it arises, we seek to conform to accepted models, and conceive ourselves in some one of the conventional and socially accepted patterns. In our efforts to conform, we restrain our immediate and spontaneous impulses, and act, not as we are impelled to act, but rather as seems appropriate and proper to the occasion (p:191).

In the same way dying people's presence in wards and staffs' work amongst these dying patients may control other people's behaviour in wards. They observed the dying patient and spoke quietly. People may have subdued their feelings toward the appearance of the dying patients. They made no comments about the dying patient in the wards. This may have in some way influenced how the staff members interacted with these patients in a relaxed fashion or nervously.

The following discussion presents further data which illustrate the display of dying in the public space of wards.



### Patients' deterioration

This extract explores a patient's deterioration. It corresponds with her social isolation:

Pat's physical deterioration is more noticeable by the day. The colour in her face is changing and the circle of discolouration around her right eye is becoming pronounced (0624:4).

Three weeks later her face is so emaciated that her lips are sunken, causing her dentures to protrude out of her mouth and hang over the lower lip. With her left hand she grasps the bell cord, which is pulled down over her chest (0717:3).

Three days later, she is still alive but because of the facial wasting, I only recognise her by walking up to her bed and inspecting her face (0720:1).

The progression of cancer physically exhausted this patient, Pat, and impaired her vocal cords. A noted conversationalist in the ward before, she was now restricted in conversing with people. Ward room-mates who knew her before the voice impairment continued to speak to her by approaching her cubicle. That changed as patients who knew her were discharged or died. Though able to communicate to the end, her interactions with people decreased as newly admitted patients arrived who assumed that she could not speak. She experienced social isolation.

A staff member shared with me a message from the sons of this patient. They rang the unit and said that they would not be visiting their mother because she was embarrassed by her state of deterioration (0720:2). Initially Pat was admitted into a single room. Reluctantly, she moved from it as it was needed for a lady she called a 'prima donna' - a younger patient. Pat was

embarrassed by the effects of her deterioration, thus her sons ceased their visits to the hospice. Still, because she was in a public ward, other people witnessed her dying. Perhaps as she deteriorated, the privacy a side room offered would have benefited her. She would have been away from the public gaze of other patients and visitors and offered privacy to die in.

The reason for care of dying patients in wards was recounted as, we like 'to keep them in here', so the 'other patients' can 'see what death is like'. However, my observations suggest that dying, not death, is displayed in wards. The management or concealment of death was discussed in Chapter 5. Responses to dying and multiple deaths will be presented in Chapter 7. The display of dying in wards influenced people's behaviour. As illustrated later in the chapter, criteria for side room eligibility effectively distinguished between types of dying and segregated problematic dying from wards. Side rooms are physically isolating, however they also enable privacy. Cumming (1968) identified physical isolation as the purest form of social control. In this situation physical isolation enabled the staff, to some degree, to determine when contact with the isolated patient was made.

### **Death Vigils**

In this section data on the public event of death vigils in wards are presented.

Death vigils are a gathering of people around a patient's bedside waiting for the patient's death. People in attendance included

relatives and friends and sometimes staff members. Lamberton (1973) recognises the support and sensitivity necessary for families remaining at the bedside of dying patients. He recommends staff members assist or remain with them. As will be seen, however, this seldom happened in the hospice, at least during the periods of my observations.

In this data extract activity in the ward is captured as three ladies begin a vigil.

Three glassy-eyed, sombre looking women walk down the main corridor. Their pace is slow as they enter the lady's ward. Two of them kneel down on the left side of the bed, facing the contorted and unmoving patient. The patient at bed 1 is confined to bed, while the lady at bed 5, next to the kneeling women, entertains four visitors (0807:3).

Neither the staff members, patients nor their visitors approached or spoke with the group of ladies. The other patients were occupied with other matters or their visitors. They were seemingly oblivious to the death vigil, or, perhaps, deliberately distancing themselves from it.

In the next scene, two death vigils occurred simultaneously in a ward. These scenes occurred during afternoon visiting hours. Other patients who were mobile were out of the ward.

An inert patient whose eyes are partially open is surrounded by three people who are facing him. One man is standing beside the bed. Another man slowly shakes his head sideways as he looks at the patient (0810:2).

Over at the next cubicle, the patient is turned on his right side. His eyes are open slightly. His breathing is inaudible. A woman is seated facing him. She is touching his hand (0810:1).

Both vigils were subdued and no staff members were in the ward.

The next data extracts illustrate that an auxiliary did not join a death vigil.

At 7.30 p.m. two men speak to an auxiliary outside the main door to ward 1. She says to them, 'Oh no, tell him you're here. He'll know'.

They were visiting the comatose man in ward 1. The auxiliary later tells me that:

'They wanted me to tell him they're here. I told them to do it' (0518:4).

These men seemed uncertain about how to interact with the unconscious patient and may have been asking the auxiliary for assistance. Desensitised to comatose states and experienced in interacting with these patients, she may have overlooked the unease the men perhaps were experiencing. Ward routines prevailed. She was settling patients for the night and was unable to accompany the men to demonstrate how to interact with the patient or support them while they did. The men left the hospice a short while after they went in to see this dying patient.

Lamerton (1973) writing about death vigils in hospices recommends that they 'must be discreetly supervised'. The response of the auxiliary mentioned above, therefore, was questionable, from

Lamerton's perspective.

Death vigils may be protracted. I argue that vigils in wards and the visibility of dying patients influenced the atmosphere in wards and interactions within them, in the same way as dying patients but with a notable difference. Death vigils, where dying patients were closer to death, contained a spiritual symbolic element which seemed to sanctify the event and is illustrated in the next data extract.

This follows the death vigil of the lady contorted in her body position over a five day period. Her death drew nearer and a patient from the ward became involved.

Four people are gathered at the lady's cubicle (1). The doctor remains with them for brief periods, in between attending to other patients. The patient is motionless. Her left eye is bruised and the discolouration is spreading to her face. A hand towel is placed on her forehead. The patients in beds 1, 2 and 3 watch the dying lady's cubicle. Out on the conservatory with another patient from that ward, I am monitoring the events within it through the window. The patient from the bed (2), next to the death vigil, leaves the ward sobbing. Her son is supporting her. She says, 'They told me that's it' ... the cancer is all over. She continues sobbing. They sit down on chairs in the conservatory. Shortly thereafter, they arise and walk back to the ward. The doctor meets them at the entrance to the ward and puts his arms around them, to prevent their entering it. In a curt manner he instructs them to 'Go and have tea' (0221:9-12).

The distressed patient asked to speak with the doctor and perhaps forced him to disclose or restate her prognosis. The death vigil in the ward may have provoked her request about her condition. Witnessing the patient dying and the crowd gathered, she may have wondered about her fate. Her emotional outburst was loud and

perhaps the reason for the doctor's response to have tea. The doctor's priority appeared to be the death vigil. He likely did not want the people in it disturbed by the emotional patient. The other patients in the ward were quietly watching the vigil.

Another relative who travelled from Australia was alone with his mother at her vigil and said:

I'm glad they don't do what they do 'in hospitals,  
wheel them off to isolation' (0620:1).

He meant move patients to side rooms to die. The moves, however, do occur and are presented in the next section.

Social rituals at death, Van Gennep (1960) notes, are 'rites of passage' which assist people through bereavements. Similarly, I argue that death vigils support people through dying. However, death vigils became ritualistic depending upon who was present at patients' bedsides. A staff member said, when death was inevitable, they left patients alone. None of the staff or family remained with the patient that she referred to. Thus she was cared for with routine physical care when dying, whereas, if people had been present, the death vigil was defined differently and may then have become a symbolic ritual of awaiting death.

Goffman (1956) refers to comatose people as 'non-persons'. This appears to be the case in the previous example with no staff members remaining with the comatose patient, in the absence of relatives. I argue that death vigils define the status of comatose patients when people, especially relatives, were present at the

bedside. The comatose patient then became the focus of attention and regained their status as a person. No matter what stage of consciousness, the comatose patient remained a family member until their death.

Death vigils are an element of routine hospice activity. Practical difficulties in a 'death watch' were identified by Sudnow (1977) in his study of dying in hospitals. He found that when families were awaiting death, a nurse remained with them. That removed her from other duties and reduced the number of staff who could care for the other patients. Strauss (1985) identified hospital work as being temporally organised. This order is affected by quick or protracted deaths. Death vigils in the hospice wards also required close supervision, so that death could be concealed soon after it occurred. This might explain why hospice staff members did not remain with comatose patients who were alone. When relatives arrived the staff only visually checked the vigil when they were in wards.

Death vigils are what Sites (1973) calls 'symbolic tactics' in which groups of people share meaning and appropriate behaviour. They are influenced by verbal and non-verbal strategies during interactions. Sites exemplifies how the cross in Christianity may induce serene behaviour and similar collective responses in people. So do death vigils.

Death vigils in this hospice were often quiet. They may elicit quietness in the wards because people were observing them. Being observed constrains interactions according to Cumming (1968).

Face-to-face interactions control other people's behaviour, she argues. Thus the presence of dying patients in wards controlled people's interactions amongst them. It was a double constraint in hospice wards. Room-mates and others in wards observed people in a death vigil and those in the vigil observed the room-mates and others. Each group of people controlled each other. Thus the observed being observed. Death vigils with relatives present, became a means for controlling behaviour in wards because they occurred in public spaces. Other people would be mindful of the ongoing death vigil and lower their voices or leave the ward for the conservatory and visit out there.

Cumming (1968) studied people seeking assistance from social service agencies and noted different behaviour when they were counselled in private or public. When clients were seen in private they were more open. When seen in public rooms or cubicles their responses were guarded. It is likely that similar responses were occurring with people in wards where death vigils were taking place. They may have held back words or gestures amongst themselves or dying patients because they were being observed in public space in the same way as Cumming noted.

During protracted death vigils some relatives desired privacy. Relatives were sometimes unaware that side rooms were available. The staff sometimes withheld information about side rooms to patients and their relatives. Thus the staff members could use side rooms to their advantage by using them for problematic dying patients in wards. This eliminated accommodating relatives who might enjoy the privacy single rooms offered. Withholding



information about side rooms suggests perhaps that the demand for side rooms was greater than their availability or that the staff wished to retain control over their use with minimum negotiation with relatives about these rooms.

### **Decisions about Public or Private Dying**

In this section criteria considered when determining whether dying was public or private are discussed. The discussion illustrates how problematic it could be to assign dying patients to wards or single rooms.

Allocating hospice patients to side rooms is reminiscent of the isolation imposed upon dying patients in hospitals. The hospice concept of wards intended to do away with this isolation. However, it occurred in this hospice. Hospice caregivers and staff interviewees were cautious in how they justified the use of side rooms. They need not be because these decisions were necessary for practical reasons like nursing care and the rooms were desired for the privacy that they offered. Side rooms were in demand for privacy needs and reprieve from witnessing other patients' dying. The data illustrate that preferential treatment was given to some patients because of the single rooms they were assigned to.

The following data were extracted from the staff interviews, observations and conversations. The staff interviewees discussed how patients were allocated to side rooms on the unit. Their responses point out the complexity of the task. Side rooms were referred to, throughout the fieldwork as: private, single or small

rooms. Wards were also called 'big rooms' because they could accommodate 6 patients.

### The unit situation

The first factor considered in room allocation is a practical one. The situation on the unit may influence which rooms patients are placed in:

... If the vacancy is in the side room, they go there. Then 'when the bed' is needed ... it's harder to move them to a 'six bedded ward' (S6).

The interviewee referred to patients initially admitted to side rooms who were reluctant later to move to wards, when and if necessary. These patients may have been scared of what they might witness in wards. She intimated the problem this type of transfer posed for staff.

S 'We have situations where folks will not come out of ambulances' which is a 'nightmare'.

TM 'Really'.

S 'Yah. It's just dreadful. But yes often they are bewildered and frightened when they arrive, because of the uncertainty of what it is, because of things they've heard about us. And preconceived ideas' (Sr5).

Needs of another group of patients were considered before their admission into hospice and from contact with the referral agency. Patients reluctant about hospice admission were given special consideration.

The side rooms are used as a 'cushion to the hospice, to bring them into the hospice' ... (S7).

These patients could be transferred into wards after they felt more comfortable in the hospice or when the room was needed for another patient. One staff interviewee claimed the Home Care nursing staff sometimes offered private rooms to their patients to bring them into the unit. She was resentful of this offer because unit staff were then faced with informing patients about their transfers to wards, if the single room was needed for another patient. This suggested that patients may be uneasy about the hospice and fearful of what they might witness and experience in wards.

#### Clinical criteria

Clinical criteria such as respiratory complications, wounds and mental status were also considered when assigning patients to rooms. A staff interviewee discussed the movement of a patient from a ward to a single room because he was experiencing respiratory difficulties. She suggested why he was moved. In this scene she discusses a difficult situation where a patient was upset by what he had observed in his ward. He believed that movement to a side room was ominous. The nurse begins by discussing patients' fears because of what they witnessed and believed that side rooms were indicative of imminent death:

N     'And also, they have seen so much in their time here and fear the thought of being moved into a single room. We got patients in at the moment who have seen some'.

TM    'What do you mean?'

N 'They have seen people being moved out. This gentleman saw two people being moved out of the ward into single rooms. And one of these situations was overnight. And he woke up in the morning not realising that the patient had been deteriorating during the night and he was most distressed. And he was told what was happening'.

TM 'What would he have been told?'

N 'He was told that the patient became ill during the night and was having some breathing difficulties, which were distressing him and he was moved for extra air and more quietness. And that he was also told that his condition wasn't good'.

TM 'Was he alive?'

N 'Yah but, not, he died later on that day. And it was after that this patient said he didn't ever want to be moved to a single room' (0815:3-4).

The dying patient was transferred from the ward because of respiratory complications. The nurse suggested that transfers to side rooms prevented ward room-mates from witnessing other patients' deterioration. However well intentioned the move was, it bothered the patient who remained in the ward, possibly because he associated the move with imminent death.

Glaser and Strauss (1965), in their hospital study, noted that patients closer to death were moved to single rooms and told intensive care was available there.

Public dialogue was noted in the words used to explain to the patient why his room-mate was better in the side room. The transfer probably helped the staff. Monitoring the patient's condition would be easier in a single room because it would not disturb other patients. So too would the removal of the body to the back room after he died. The staff members' work would be

easier, by the move to a single room, because less patients would witness the man's dying, as would not be the case from wards.

Wounds are another clinical criterion for determining which patients were placed in single rooms. Some wounds caused odours in wards which may upset other people. Patients with wounds may initially be placed in wards. These patients have a 'wound' (S6) or 'malodourous' condition that is 'nasty, smelly fungating' odours, present in some types of cancers (A1). By placing them in single rooms, the patients obtain privacy and it may be easier for nurses to dress the wound and store supplies. Patients with odours sometimes remained in wards. References were made by staff members to one lady's odour smelling like a tom cat. In these situations mechanical devices which extract the odours were located nearby. Some patients with wounds were placed in single rooms, whereas others remained in wards.

Patients' changing mental status could be disruptive so it was also considered when assigning patients to rooms. These patients qualified for side rooms:

'Noisy, confused, demented patients that would disturb others in a ward' are moved to side rooms (NA4). These patients are 'fractious', annoyed by noise or create havoc to others (NA29). They are the 'patients who are a bit disruptive through confusion' (S6). Moving them to single rooms benefited people in the ward who were then not exposed to this disruption. Room-mates in wards might be frightened by these patients' confusion. Patients who were upset and reacted to the dying and multiple deaths that they

witnessed could be placed in this category. Their disruption could disturb their room-mates. These patients disturbed the peaceful atmosphere that the hospice attempted to portray.

#### Patients' age

Patients' ages were another factor taken into consideration when assigning them to rooms. Preferential treatment seemed to be given to younger patients who were more frequently assigned to single rooms. A staff interviewee described what happened when young and elderly patients were mixed in wards and why younger patients were often admitted to single rooms:

'Really to protect them. There's a terrific feeling of sympathy and compassion that comes from the other patients. The older group that we have in' when a young person comes in, 'they feel terrific compassion, they want to mother, to care for that person which is good but that young person ... need some time on their own' (SR5).

Placing younger patients in single rooms spared them the attention elderly patients might pay them. A colleague suggested that younger patients required privacy for the following reason:

'Particularly young patients', although 'the majority of patients tends to be older'. The young might need the 'privacy' to come to terms with the illness (SN6).

She intimated that elderly patients' needs differed from the privacy needs of younger patients.

Another interviewee specified that age is not the only reason for placing patients in single rooms. Instead, she believed that any patients who had 'recently been told their diagnosis' qualify for single rooms (SN6). The disclosure of the diagnosis was a factor considered when placing young patients in single rooms. Seemingly only young patients required the privacy, in these circumstances, that side rooms offered.

Other research reveals how age influences patient care and staff responses. In Sudnow's (1977) study of hospitals, he found that staff members sometimes cried when children or middle class patients were brought in 'dead on arrival' to an Emergency Department. Younger patients received more personal attention from nurses according to May's (1991) study of nurses' relationships with terminally ill hospital patients.

#### The dilemma in public or private dying

Allocating rooms to patients was problematic and created a dilemma. If patients required privacy they were isolated in side rooms. Yet, side rooms contradict hospice philosophy because one of the objectives of the hospice movement was to banish isolation of dying patients. If patients share wards then their deterioration was displayed before and witnessed by the public. The only available privacy in this situation was by closing the curtains. This rarely happened other than for provision of personal care.

The issue of where dying patients were placed was contentious amongst the staff interviewees. Some reluctantly acknowledged that

dying patients were cared for in side rooms or were moved from wards into them. The next account points to the dilemma about how the wards and single rooms were used.

N '... I think if I were choosing to design a unit, I would design primarily single rooms, accommodation'.

TM 'Why?'

N 'Because of the privacy and the needs of patients ... And given that it's the end of their life, I think it's very sad that we can't always give that. There are situations where people need people around them, other patients and they can find great benefits, but more and more, I think they appreciate privacy ...'

TM 'Doesn't that defeat the purpose of the hospice, the concept of the hospice?'

N 'Of the togetherness and sharing. I don't know, I think you can still achieve that, provide some, some place of quietness, that is their own private place ... It's sad to have rules, definite guidelines, rules for single and shared rooms and it should be more flexible and dependent upon what the patient needs, but most of them would want a single room' (Sr5).

She recognised patients' need for privacy and believed single rooms could offer that. The necessity of establishing guidelines for assigning rooms on the unit suggested that the demand for single rooms may have been greater than their availability.

#### **Patients' and Relatives' Views about Public or Private Dying**

Presented in this section are patients' and relatives' views on wards and single rooms. Two patients currently in wards discussed their advantages and disadvantages. Both were alert at the time of these discussions. I introduced the topic of single rooms:



TM 'One of the patients told me he'd prefer a side room. What do you think about that?'

P 'You mean you're on your own in a side room? No, I like my room. There's always something doing. You hear all the nurses' stories about their boyfriends' (0603:5).

This patient was elderly and alert. She was into her third week since admission and generally spent most days in the conservatory, often by herself. Thus she appreciated the staff presence, bustle and their conversations in the ward. Another patient explored the advantages and disadvantages of single rooms. He was unaware that side rooms were available, although this was his second admission to the hospice for palliative care:

P 'Oh, I didn't know there were side rooms, singles. Even in a side room you're on your own'. Prone to 'melancholy, all on your own ... Single room is good if you're out and about. You could do your toilet in privacy ...' (0603:1).

Both patients were unaware of the existence of single rooms. The second patient recognised the advantage of the privacy that side rooms offered. He identified the disadvantage of side rooms as inducing melancholy.

The next data excerpt refers to a death vigil. The relatives consider the privacy needs of their unconscious relative who is currently in a ward.

A couple are sitting beside a comatose man's bed. This vigil is into its second day. The woman tells me, 'We're just waiting for the minute'. The lady says that the patient has been unconscious since yesterday. The doctor told them that he probably 'won't come

up again'. Our conversation continues:

TM 'What do you think about being in this room?'

L 'Oh, it's alright'.

TM What about a 'single room?'

L 'We thought they'd put him in a single room near the end'. We asked 'the doctor', but he said we like 'to keep them in here', so the 'other patients' can 'see what death is like'.

TM 'How do you feel about that?'

L It would be better for him in a 'side room' (0520:11-12).

This data extract reveals what wards were intended for, seeing what death is like, the chapter title was derived from it and it illustrates the conflict between relatives' desire for a single room and the doctor's authority. The lady thought the patient would be moved out of the ward as death approached. The patient was not expected to 'come up again', meaning become alert and out of the coma. However, the doctor explained that patients close to death remain in wards, so the other patients can see death. Because this patient was restfully comatose he was an exemplar for other patients. His dying was displayed in the ward and witnessed by other people. These relatives may have desired the privacy of a single room for themselves; however, they stated 'it would be better' for their relative, the patient. Since the patient was comatose, it presumably did not matter to him where he was cared for. The previous chapter illustrated the concealment of death on the unit. Contrary to the doctor's explanation, it therefore was not death that patients would see in wards but dying.

Relatives in the following scene discussed the fact that their father was admitted into a ward where multiple deaths were occurring. On the day of their father's admission, another man died. They were upset and believed that their father might also have been. He lapsed into a coma the next day. The following death vigil took place on a hectic day in this particular ward which illustrates what patients were exposed to. A man died two hours after admission, following this conversation. The patient's two sons and I are conversing:

TM Was this room your choice?

2 They just said, 'we have a room'.

1 'Are there small rooms?'

TM 'Yes'.

I point to the side rooms through the open ward door.

2 I think when they get to 'this stage it's' better for 'him' and 'the others' if he's in a 'small room'.

The one son desired privacy for his father and believed it would be better for him in a small room. This wish may have been for privacy for the family. The son recognised that other ward room-mates witnessed his father's dying.

The wife of one of the men joins us. She is brought into the discussion as I introduce myself and the background to our conversation. I ask her:

TM Was this room your choice?

W I think now he'd be better in a small room.

TM Would you prefer it?

W Yes.

She nodded her head in agreement. She acknowledged her preference for a small room.

TM Better for family?

W Yes. More 'privacy'.

TM Are you planning on 'staying round the clock?'

1 Yes. A small room would be better with all the 'coming and going in the night' (0527:5-7).

The wife acknowledged that privacy for the family would be available in a side room. She implied that it was not in a ward. This family considered their father, other ward patients and themselves in their desire for a side room. Death vigils were visible and witnessed by all people who entered wards, as screens were usually open around cubicles. This family acknowledged that side rooms would offer privacy, implying that it was hampered in public wards. They also recognised the potential disruption to patients if they remained with their father during the night. It might disturb other ward patients. Relatives' intimacies and emotional expressions with dying patients were perhaps impeded by other people in the ward observing them.

Transfers from wards to side rooms

The following data extracts were taken from patients, or their relatives, who were in single rooms. They discuss their views about the use of side rooms.

Patients' transfers from wards to side rooms are discussed first. Patients and relatives spoke about and interpreted the meaning of transfers into side rooms. The first patient was in a ward and discussed the meaning of two patients' disappearances from her ward. She claimed that when their beds were empty in the morning, she assumed that they both had died. However, later she learned that one of them had been transferred to a side room (0717:5). She interpreted both empty beds as indicative of their deaths. Patients in wards were sometimes confused by the movements of their room-mates and unaware whether they were discharged from hospice, transferred to a side room or had died.

A similar interpretation was made by patient Sally who believed transfers to side rooms indicated imminent death. She was fearful of being transferred to a single room. In hand-over report a staff member discussed the reason:

'... She's stated she doesn't want to be moved to a single ... she was talking about Jane dying and that will be me' (0315:14).

Jane shared a ward with Sally. Jane was transferred to a single room where she died. Sally believed the same fate would be hers if she moved to a single room. Sally was later transferred into a

single room and identified its advantages:

TM 'How do you feel being in a single?'

S 'Oh brilliant. Great. It's better. I feel I don't have to watch everybody ...'

TM 'You've seen a lot of people die since you came in'.

S 'Oh, aye. More than I should. More than I'd like. That got me frightened. Oh, will that be me next ...' (0330:8-9).

Sally, a younger patient, shared a ward with elderly women. While there she tended to them as their physical conditions failed. Multiple deaths occurred in that ward, which Sally witnessed because of her extended admission. Multiple deaths are defined for analytical purposes, as the repeated exposure to the deaths of other patients in the hospice. They are discussed in the next chapter. The side room shielded Sally from other patients' deaths and offered privacy.

A relative of Sally's spoke about the move from the ward to the single room:

'She's a lot happier in here. You see a lot more than you want. She said she actually likes it in there' (0317:6, 9).

She stated that Sally was happier in the side room. The relative referred to Sally's witnessing the dying and multiple deaths in the ward as a disadvantage.

What became clearer was that assumptions were made by the patients about empty beds in wards and transfers from them, without

communication from the staff about this movement. Patients assumed that empty beds in wards meant death but, as the data illustrated, they could also mean transfers. The staff members were transferring dying patients to side rooms to die in and other patients were aware of it. Or, they were aware, from their hospital experiences that that movement occurred in hospitals. Alert patients adjusted to single rooms and recognised their advantages, as did relatives. Some patients, however, feared they would be lonely in a single room.

In the next scene a relative recognised the advantage of her mother-in-law being in a single room rather than the ward that she was transferred in. I am in a single room with a patient who appears to be comatose, as a couple enter the room. The woman asked me, Can I talk to her? 'I'm her daughter-in-law'. The woman continues and explains the reason for her question:

W It's just that she becomes noisy if we talk to her. I was hoping they'd move her. The others are better than she.

TM And more 'privacy' for you?

W Oh, 'no. For the sake of the others' (0703:2-3).

This patient was noisy in the ward. The relative believed other ward patients were disturbed by her noise. I wondered if perhaps the daughter-in-law herself was upset by the noises her mother-in-law made in a public ward, rather than the effects of them on other patients.

In a continuing care unit, James (1986) noted that patients were routinely moved to single rooms when they became comatose. Some of the patients died during the transfer.

Patients' views about side rooms

In this section the views of two younger patients admitted to side rooms are discussed. One patient spoke about her accommodation in a side room. She could not escape thoughts about her terminal illness.

P I guess it's the 'fear of the unknown' that's 'frightening'. They keep telling me it's 'stress'.

TM Does your 'stress increase' being in a side room?

P No, 'it doesn't increase my stress'. I need my 'privacy'. I guess it doesn't help 'being alone'.

TM What would you tell them about stress?

P 'They say you've got to come to terms with the illness. It's just putting it to practice. No one knows how it is until it happens to them' (0603:11).

The next young patient had been admitted to the hospice several times and usually into single rooms where she is now.

P I think that would cripple me being put in a ward. 'Seeing all that'.

TM 'Have you always been in a single room?'

P 'Yes. So it's true'. What you don't see doesn't really 'bear witness on you' (0317:14-15).

She had been shielded from death in wards because her admissions were into single rooms. The full impact of her illness could be



evaded in single rooms because she did not witness others dying not having been in wards herself.

## Discussion

This discussion examines how displaying dying sensitised people to dying and was an objective of care in wards. The role of single rooms in achieving this goal is examined. This goal was stated by the doctor who explained that dying patients were left in wards so that room-mates could see what death was like. However, they witnessed dying not death.

The presence of dying patients in wards sensitised people to patients' deterioration. A peaceful setting for displaying dying in wards was striven for. Dying in wards gave the impression that dying and death were confronted openly in the hospice. The previous chapter revealed that death was managed, when possible, so as to be concealed. This chapter revealed that selected dying patients remained in wards because they were peaceful, as in the case of Abbey. Abbey's dying was exemplary and did not disturb the ongoing events in the ward. Many patients that the staff chose to leave in the wards portrayed a favourable image of dying. Parkes (1979) points out that patients may be reassured by seeing other patients who are not suffering as they did. However, this cannot always be ensured. Parkes' claim supports my proposition that displaying dying sensitised people to dying and could control their behaviour in wards.

Dying on the hospice unit was managed by the staff to be public or private, as determined by which rooms patients were admitted or transferred to. In wards it was public, whereas, in side rooms it was private. More 'presentable' dying patients were displayed in the wards. This included exemplary dying patients and death vigils. Some relatives in death vigils desired privacy that was unavailable to them in wards. Allocating rooms to patients was fraught with problems. Criteria were established about where and which patients were admitted to or transferred from side rooms. Establishing criteria for side room eligibility effectively distinguished between types of dying and it segregated problematic dying. More 'presentable' dying patients were located in wards. Problematic dying was the problem which could be resolved by a move to side rooms, where these patients were out of the public gaze. Because side rooms were limited in number, this wish could not always be met. In side rooms privacy was available for patients and their relatives. The negative aspect of this privacy was that it isolated and segregated these patients from others. In this hospice, I argue, wards were where the image of dying was displayed. When the dying became noisy, unsightly or smelly, patients could be moved out from wards for the privacy single rooms offered.

Transferring problematic patients to side rooms resolved difficult situations in the wards. These transfers were a control mechanism that sanitised and determined what type of dying was witnessed. The transfers sometimes confused some alert patients who associated the move with their room-mate's imminent death. Side rooms were also used for other reasons, like patients reluctant of hospice

admission, which suggest patients may be frightened by the meaning they attached to the hospice. Transfers to side rooms enabled the staff to maintain order in wards. Placing problematic dying patients in side rooms may also have benefited the staff because they would have less people to explain a death to when it occurred.

Death vigils played an important role in the sensitisation process. Their spiritual symbolism often contributed towards quiet behaviour which was noticed by people in wards and their behaviour often aligned with that. Death vigils were 'spiritual symbols' which Bruyn (1966) argued reflected suffering. When death vigils were closely supervised, death could be concealed as it occurred. The staff monitored death vigils while attending to other tasks in the ward or walking through it.

Although patients may have preferred wards before they became comatose, the needs of their relatives may be for privacy during the death vigil. This raises the question of whose needs were placed first. Leaving death vigils in wards so that others could see what death was like, took into consideration the room-mates rather than the needs of relatives of patients nearer to death.

Some patients and relatives were unaware that side rooms were available. According to the staff interviewee, side rooms were in greater demand than their availability. Restricting information about side rooms safeguarded staff from negotiating and turning down requests for them. This gave the staff greater control in determining who received these rooms and how they were used.

Wards enabled patients to witness dying. Witnessing dying patients and death vigils presumably sensitised people to dying. The objective was to positively influence their behaviour in wards. In the next chapter the negative influences of this exposure are discussed. To realise the objectives of sensitisation, the staff assessed which patients were appropriate for care in wards. Those patients who were deemed inappropriate were transferred to side rooms, if they were available. The sensitisation process of displaying dying was essentially sanitised by selecting those patients suitable for wards and those for transfer. What remained was an image of what the staff attempted to portray dying as.

The doctor's reason that the death vigil remain in the ward was seemingly altruistic, for the benefit of others. His reason confirmed that dying was displayed and why. In the same vein displaying dying also became a show-piece for visitors, like health care professionals who came to observe what dying was like in hospices.

'Displaying dying' was the theme of this chapter which identified the purpose of displaying dying patients in wards so that others could witness dying.

CHAPTER 7

'THEY'RE JUST DYING LIKE FLIES' :  
RESPONDING TO DYING AND MULTIPLE DEATHS

## Introduction

The chapter title is a patient's response to the multiple deaths she encountered in the hospice. The chapter deals with patients' and others' responses to the dying and multiple deaths in the hospice. Multiple deaths are defined for purposes of the analysis as the repeated exposure to the deaths of other patients. The term is one that I have developed, not that of other authors. Mentally alert patients were exposed to and aware of these multiple deaths which were relevant to their well-being.

The chapter reveals patients' and nurses' responses to the multiple deaths and the dying of other patients that they witnessed. An increase in alert and attentive patients being admitted to the unit was noted by the staff members. Because of their alertness and protracted stay in the hospice these patients may encounter repeated exposure to dying and deaths. Alert patients in wards witnessing dying and multiple deaths, I argue, was creating problematic situations which challenged traditional hospice ideology of ward care. Care in wards was believed to benefit patients but, as will be shown in this chapter, it was problematic. Arguably, the hospice ideology was to break the death taboo by caring for patients who were dying in a secure environment. The question now raised is whether the demands of this ideology can still be upheld in the face of changing circumstances, with so many more alert patients using the hospice facilities. Hospice care seems to be moving towards palliative care in the early stages of cancer and chronic disability conditions, in addition to terminal care. The mix of these patients in wards, many of whom were alert,

exposed them to situations which could be seen as detrimental to their well-being.

The chapter begins with three case illustrations of patients' reactions to dying and sequences of deaths in wards that they witnessed. It shows how three patients' situations were managed by staff members, who adopted strategies to alleviate the situations that the patients were confronted with. Staff members' experiences with multiple deaths are also examined. The differences between past and present supportive care in this hospice are discussed. Supportive care is similar to psychosocial care. Supportive care refers to meeting psychological needs and in this thesis, especially related to the dying and deaths patients witnessed. In the responsive phases later in the chapter, both the positive and dark side of hospices and the relation to life and dying are presented.

### **Encounters with Death**

Patients' encounters with deaths in their wards are presented in this section. Their responses reveal how they and the staff recognised their upset because of the deaths they witnessed.

#### Elspeth's case

The following data extracts are taken from Abbey's story. Abbey's story was introduced in Chapter 1 of the thesis. The extracts reveal how Elspeth, another patient, was unsuspecting of Abbey's death and how she became informed of it, without any communication

from the staff members. It was the first death in the ward since Elspeth arrived at the hospice.

After confirming Abbey's death at bed 1, I joined Elspeth at her cubicle (4). Abbey's screens were closed. My objective was to establish whether Elspeth knew about the death or how she became informed of it and her response to it.

Elspeth was finishing a cup of tea. I sat on a chair beside her bed and after a while asked her, 'Do you know why the curtains are closed?' The question was intended to explore whether she knew about the death. We both looked over to the cubicle. 'No. They not just working with her?' (When personal care was being given the curtains were often closed.) Elspeth continued peering at the cubicle. 'Ah yes, they will. Do I not see somebody's feet?' (The presence of feet on the floor would indicate that somebody was in the cubicle.)

She mistakenly believed someone was behind the closed screens working with Abbey. Elspeth moved her head down to the right and close to the bed, trying to gaze under the closed screens, looking for someone's feet.

Elspeth changed the topic to questioning me about the length of my shift that day. The conversation deflected the focus from watching the screened cubicle. She also commented on the food at the hospice. As she spoke, again she stared over at the cubicle, trying to look under the screens. 'The screen's around. Do you think she's alright?' asked Elspeth. 'I don't know. What do you



think?' I asked. 'I know she was very ill today', continued Elspeth. Her comment suggested that she was questioning Abbey's present status. 'Very ill' could be public dialogue for dying.

Ten minutes later the doctor slipped behind the closed curtains. I remained at Elspeth's bedside. Elspeth looked up from the tabloid she was reading and watched the cubicle. Sister briefly joined the doctor and then left.

'Something must've happened. There's a doctor in there', Elspeth said. Members of the staff entered the ward. Elspeth lit a cigarette. 'Something happened', she repeated. She appeared agitated.

A staff member spoke with the patient in bed 2, next to the screened cubicle. She said to the patient, 'Aye. Abbey died'. Abbey and she were friends. We overheard the comment.

'I feel it. Sad. I didn't know her', Elspeth told me. 'What did you think happened?' I asked. 'Well, I kinda thought. When there was nobody there. Didn't you?' 'Yes', I replied. I knew about the death but wanted to establish how she became informed about it. 'I kinda thought', Elspeth repeated. She broke eye contact and stared at the closed screens. 'Is this the first one since you are in?' I asked. Elspeth nodded her head, adding, 'that I know of' (0615:8-14).

Elsbeth was not told about Abbey's death, at least while I remained in the ward until her body was removed and for a half an hour after it.

### Eilish's case

This case is constructed from data extracts which highlight patient Eilish's encounters with multiple deaths in her ward, her responses to them and the actions taken by the staff. Eilish's admission was a repeat and presently at the time of this experience was protracted. She had Motor Neurone Disease (MND). The admission being described was her first into a ward. Previously she was cared for in single rooms. This change was the hospice's attempt to try to integrate MND patients with other patients in the wards.

The scene began with my discovering a death in a ward, that the staff were aware of, where a bed was missing from cubicle 3. I returned to the duty room for the hand-over report. Sister acknowledged that three deaths had occurred during the night. She then reported on Eilish, a patient from a ward where one of the deaths occurred. A nurse added, 'there's been a change in her. Bit sad with the deaths going on in there, but not bad'.

They had noticed a change in Eilish because of the death. The Sister's comment was followed by reference to the recent sequence of deaths in Eilish's ward, possibly linking the deaths with her response.

A nurse asked about the medication, Scopalamine. She wondered how often it could be administered. Another nurse responded by reading out loud from the drug package insert.

A symptom of the MND which Eilish had was copious saliva production. Scopalamine controls the secretions. The nurses deliberated about how often it could be administered.

An auxiliary said, 'That's the second she's seen'. Eilish had now seen two deaths in her ward. Sister Kate said, 'She needs a one to one. Doreen, you do a one to one with Sister Shona'. A one to one meant one staff member worked closely with a patient. In this case two staff would be working with Eilish. Another member asked what happened. Sister Shona responded:

She 'screamed' before she died. 'I apologised' that we weren't there. She was 'holding her hands'. (Sister held her hands together.) I 'asked her if she was praying'. She nodded.

'She' in the above extract refers to Eilish who witnessed the patient's death that morning and screamed as she died. The staff were not in the ward at the time of death. When they did arrive, they found Eilish praying (0203:2-3).

Eilish's saliva production may have increased since she observed the death and that is why the nurses queried how often Scopalamine could be given. Perhaps her increased saliva production was a psychosomatic reaction, where the stress of the death manifested in a physical symptom, increased saliva production. Stress can exacerbate disease processes, although changes in saliva production

could also be a progression of Eilish's disease.

Five days later, Eilish was reported on by a senior Sister as being bothered by the events in the ward.

'She's swinging the staff. Insecure with what's been going' on there and she's 'not in a single' (2005:7).

The staff attributed Eilish's continued upset to the multiple deaths in the ward and her not being away from it in a single room.

Seven days later, two more deaths took place in Eilish's ward. The following discussion about Eilish was held between two staff members in report:

- 1 'She's swinging the lead with some of the staff. She's been told to stop it'. (She pulled a sheet of paper off the bulletin board.) 'This is her diet'. She's drinking fluids instead of eating. (In raised voice) 'She's lazy'. This is her diet and 'what she gets'.
- 2 'What if she wants something else?'
- 1 'Assess her. Claire said she's sad. She's going down quick' (0210:6-7).

Assessing the source of Eilish's sadness was problematic, as she may have been depressed because of her illness. Her poor appetite may have been a symptom of depression. Claire, Eilish's room-mate, and a staff member recognised Eilish's deterioration. The question was whether the deaths had influenced Eilish's state. The staff members attributed the change in her to the sequences of deaths in the ward.

Eilish was not taking her diet, which may have been a response to the multiple deaths that she witnessed. The nurse attributed it to her being 'lazy'. Another patient, Claire, believed that Eilish was saddened by the deaths. I believe that the deaths affected Eilish.

The strategy implemented by the staff was to move Eilish out of the ward where the multiple deaths were occurring and into another ward. This appeared to me to be a short term solution which worked. The move seemed successful for a month until another patient's death occurred in the second ward. Transferring patients about the unit was not always possible because beds were not always available. It was also an impractical measure for managing patients' reactions because of the extra work it created for the staff members. This move seemed to contradict hospice philosophy of placing patients in wards.

Eilish seemed distressed by the death in the second ward. She scribbled the details of the death on a writing pad, as her disease prevented her from verbally communicating words. She showed the pad to people who approached her bed. The staff recognised her upset. That evening in report, two nurses discussed her state:

- 1     'She knew what happened by the look on her face ...  
      Was deeply upset ... quite upset by Dora's death'.
- 2     'Well that's why she moved from room 1' (0313:7, 9,  
      11).

They recognised that Eilish had witnessed Dora's death and was upset by it. Eilish had been transferred to the second ward

because of the multiple deaths in the first ward, as identified in the extract above and now death occurred again in the second ward. Eilish could not get away from deaths. Within a few weeks Eilish herself died.

#### Sarah's case

Sarah, a younger patient, also encountered multiple deaths in her ward and, like Eilish, was transferred between wards. She shared with me the distress that she experienced because of these deaths. A nurse overheard our conversation but limited the information she related about the incident to senior staff members.

Sarah was seated in the conservatory. She looked agitated. Her right leg was visibly shaking. I sat across from her but faced away and wrote in my journal, while observing her in my peripheral field of vision. I was uncertain of the meaning of this observation. Sarah looked at me and said:

S     'It's depressing in there. They're all old women. I know they're ill but ... Putting me in there with all those old women'. Every time you turn around 'one's away'.

TM    'What do you mean?'

S     'They're disappearing ... Dying off ... Ah, that's so depressing. I know we all got to go but they shouldn't advertise it. I wouldn't like to go that way. No way. If they could put me with someone my own age. It's so depressing ... Everytime you look up one's away. They're old, old, old women in that room. I'm saying, am I due to go? That's the impression I'm getting. That wouldn't put you forward, that would set you back'. (She points to ward 3). 'I wouldn't want to die amongst old, old women. There's another one away'.

TM    'Where, in there?'

S 'You see them dying off like flies. It shows you how much hope there's for me ... I don't know the reason I'm here ... You're learning from a patient who's experiencing it. You can't mix old with young. You're always hoping for a miracle. I'm getting to the state where miracles aren't going to happen. Miracles are a myth'. What do you do? I 'just lie awake at night and there's another one gone. They're just dying like flies. That would give you no miracles, cause you always expect miracles. You want to take your mind off it. In the morning you wonder if there'll be anyone left' (0312:15-18).

Two days later Sarah is reported on by a nurse to a doctor:

N She doesn't like it in there with all those old women.

D Did she tell you that?

N 'She was speaking to you Therese, wasn't she?'

I acknowledged that we were.

N Can't she go back?

D 'They're not normal people in there. Do you know what the twentieth floor at the (Psychiatric hospital) is like?'

The nurse only mentioned that the women's age upset Sarah (0313:112). She failed to report the connection between Sarah's distress and the deaths in the ward. Because Sarah arrived at the hospice from a psychiatric hospital, the solution proposed by the nurse was for her to return there.

Sarah's youth and denial of her condition were juxtaposed against the elderly women in her ward who were 'dying like flies' and in whose company Sarah believed she did not belong. Sarah's denial of

her condition bordered on panic, as she witnessed the multiple deaths of her elderly room-mates. This case suggests that external events in the ward, such as the elderly ladies' dying, bothered her.

There is no way of knowing how much of the conversation between Sarah and I that the nurse heard. The nurse mentioned that the women's age upset Sarah which, decontextualised from the other information is a minor point, although suggestive perhaps of Sarah's denial. More importantly, the nurse failed to report the connection between Sarah's distress and the deaths in the ward. Perhaps the nurse was prompting me to divulge the details of the conversation that Sarah and I had. I was unaware of any communication about these events between Sarah and other staff. So, Sarah appeared to be left to witness the dying of others and come to terms with her prognosis alone.

In my judgment, regarding supportive care, there were two events when it could have been provided: Sarah's denial of her condition and support in coming to terms with the ongoing deaths in the ward. Sarah became a problematic patient and her case exposed the weak supportive care which I observed in this hospice. The easier solution was to send Sarah back to the psychiatric hospital rather than dealing with the situations in the hospice that required supportive care. It is unfair to blame psychiatric illness as the cause of Sarah's distress. Perhaps because of it Sarah was able to identify her distress.



### Discussion of the three cases

The three cases presented above illustrate how patients' responses to witnessing death varied. They also reveal how the staff members managed the cases. The strategies employed by the staff to deal with patients' responses to death was either removal to another ward or to ignore the patient's dismay. Communication with the affected patients was not a feature of the staff's strategy as far as I observed.

The purpose of Eilish and Sarah's transfer to another ward was to remove them from situations of multiple deaths. The strategy was successful for Eilish until another death occurred in the second ward. The multiple deaths Sarah discussed with me were not included in the nurse's report to the doctor. With Elspeth the strategy was to conceal Abbey's death with closed screens. The staff did not discuss the death with her. The staff did not speak to Elspeth about Abbey's death. Eilish's case highlights that communal care in wards can be problematic because of multiple deaths and that the strategy to remove Eilish to another ward was unsuccessful when death occurred in the second ward. The policy to integrate patients with MND with other patients in wards was problematic because the progression of these patients' illness was slower than cancer patients and the MND patients were mentally alert to events in wards. The response to Sarah's upset was linked to her room-mates' ages, not their deaths. No mention was made of the multiple deaths in that ward. Sarah was viewed as a problematic patient and the problem of deaths in the ward was not identified as problematic.

Vernon (1970) notes that societies play down fears. Any society employs fear control procedures. These mechanisms or procedures diminish or resolve fearful situations. Eilish was frightened by the multiple deaths she witnessed. The staff either played down her fears, did not understand them, or ignored them. The procedure that they employed to resolve this fearful situation was to transfer Eilish to another ward. It was successful only so long as death was held in abeyance in the second ward.

Saunders et al (1981) address the feelings of patients with MND and nurses' distress at sequences of deaths. They suggest both groups might be supported by sharing these feelings. MND patients may be affected by the death of nearly every patient they form a relationship with. Saunders' suggestion requires open communication, about deaths, by the staff.

These case illustrations point out that if patients respond to multiple deaths on a large scale, how many patients are dying upset because of what they have seen?

### **Recognition of Multiple Deaths**

The recognition of multiple deaths is explored in this section. The staff interviewees recognised that patients were alert, aware of their surroundings and that repeated exposure to deaths affected them. They described reactions that they observed in patients. In the following extract, a staff interviewee believed that patients were not prepared for the multiple deaths which they encountered in the hospice.

'These people are coming into the hospice, and they're seeing so many other people dying. It must have some effect on them. Somewhere. And they get frightened. I think that's really why and then they become so agitated. I think a lot of that is fear, of what they have already seen. They've seen too much actually. And I don't think anybody prepares them for what they're about and what they see in the hospice' (NA1).

This nursing auxiliary believed that patients were frightened and agitated by multiple deaths. Another staff interviewee acknowledged patients' fears in the hospice:

'... as everywhere in modern society, they're frightened of, of dying. Frightened of death. We are a society which is uncomfortable with these things' (A1).

Her colleague, a Sister, agreed and cited how patients kept records of deaths they witnessed:

'They can't see further ahead to the fact that patients are seeing many deaths. And if they're in a main room, very often a great number of deaths in a short space of time. And we've had patients who have actually kept notebooks with the numbers and names of people dying' (SR5).

This interviewee felt that witnessing sequences of deaths in wards caused patients to wonder, 'Very much, when am I next. They feel bereaved because they've known that person' (SR5).

Another interviewee, a nursing auxiliary, interprets why patients might say, 'They're just dying like flies'.

'I think when somebody says something like that it's because they feel like and wondering and worrying if it's going to be' them 'next' (NA1).

The staff interviewees recognised that in wards patients witnessed multiple deaths. Patients were unprepared for this, felt bereaved by witnessing multiple deaths and that caused fear and agitation.

I argue that alert patients who witnessed multiple deaths in wards were experiencing problematic situations. The strategies employed by the staff in these circumstances seemed to be short term and did not directly deal with the problem. Patients were unprepared for the deaths that they encountered in wards, according to the interviewee. Attempts were made by the staff to prevent patients' fears, by removing problematic dying patients from wards, but they were only partially successful. The psychosocial care that is claimed to be practised within hospices does not seem to encompass the dying and multiple deaths that occurred in this hospice. Whether the event of preparing a patient for their own death, never mind the deaths of others, occurred in this hospice is questionable.

Emotional care was a priority of nursing that Florence Nightingale recognised. Her 'frequent admonitions to let the patient know what he can expect, what will happen to him, reflect her interest and concern for the patients' emotional state', according to Dolan (1969, p:viii). Communication with patients about what will happen to them may influence their emotional state. This is surely a component of what is described as psychosocial care in hospices.

Patients' psychosocial problems were heightened when they knew they were dying, according to the following authors. Depression often followed disclosure of the terminal illness, Glaser and Strauss (1965) found. In this study the external events of room-mates' deterioration seemed to be a factor in patients' responses. I argue that external events that were witnessed in wards did influence patients' responses. External events such as respiratory problems ongoing dying and deaths interrupted patients' sleep or patients anticipated that it would. In the case illustration of Sarah, youth, psychiatric illness and witnessing multiple deaths may have contributed to her anxiety. Thus external events were involved in her distressed response. The staff were aware of patients' seeing the dying but, beyond that, no consistent strategy had been worked out to deal with it. Whether or not there is a strategy which could alleviate patients' anxiety about multiple deaths is debatable. The point remains, however, that their occurrence makes it difficult for hospice philosophy to be implemented.

#### Staff members' responses to multiple deaths

The staff interviewees were asked how they would respond if a patient said to them, 'they're just dying like flies'. The first staff member appeared to understand the phrase but was uncertain, if placed in the position, how she would respond:

'Well I would but I would just say well, they all, they've come in very ill and that. That's a difficult one isn't it, really? Most of them know they are coming into a hospice. They are going to die but, if you say, when they say that, it means that there's been more than, just one or two in the

ward. So it means that there're. Big concentration of deaths around them. I just really don't know quite how I would answer that one to them' (NA1).

The interviewee was uncertain of her response. She acknowledged, however, that multiple deaths occurred in wards.

Another staff member was more certain of the action she would take if patients spoke about multiple deaths to her:

'I wouldn't say a word to them. I'd turn and walk away' (NA29).

She was then asked how she would react if she were in the patient's position with deaths occurring around her.

I'd have the screaming adabs'. I'd want to 'go home. I think it would be very depressing' (NA29).

Her comment raised the issue of the effects of death, not only for patients but also for the staff members. This nursing auxiliary's response to sequences of deaths was hypothetical but revealed a double standard. If patients spoke of their dismay about multiple deaths, she would ignore them and leave the room. Yet, if she herself was placed in the patient's position, she would not want to remain at the hospice.

These data extracts challenge the whole hospice ideology of psychosocial care. Multiple deaths were a feature in the hospice. It appeared that supportive verbal exchanges about multiple deaths between staff members and patients did not occur. The nurse in

Sarah's case earlier in the chapter may have ignored the multiple deaths that Sarah was upset over. An opportunity to provide supportive care related to the multiple deaths and Sarah's denial was missed.

This raises another issue. Hospice care proclaims the success of a high ratio of staff members to patients. The advantage of it may well be in the provision of physical care alone. In the three references to staff members in this section, two were nursing auxiliaries and one was a qualified nurse. The two auxiliaries may be unaware of what psychosocial care was expected, whereas the nurse should have been. A high staff ratio does not seem to guarantee psychosocial care or quality care that hospices proclaim.

Glaser and Strauss (1965) suggest that nurses are affected by the deaths of patients. There are therefore two groups whose needs must be met, the patients and nurses. Not only were the patients disturbed by the deaths, they also created tension and stress for the staff members. Hillier (1983) recognises the sadness which staff members may experience at the death of patients. He recommends support of colleagues and senior staff members.

The changing situations that were identified were a challenge to hospice ideology. Whether ideal care can be delivered with these changing circumstances is questionable, as the staff identified problems that they created.

The effects of death on staff members

The discussion moves to staff members' responses to deaths on the unit. Support for caregivers in an environment of ongoing deaths is as essential as the support necessary for the patients. Whether support was available from within the hospice hierarchy for the workers was questionable. Several staff interviewees recognised that deaths affected the staff members:

'The nurses' are 'stressed'. They discover it when they leave here and begin 'crying'. They wonder why, then think about what happened at work. They're too busy at work to think about it (0731:3-4).

Another colleague said:

I don't know how the young ones cope. 'The tension builds. Who takes care of the carers?' (0104:6-7)

The staff were stressed by deaths and their work with dying patients, according to these members of the staff. This raised the question of whether their ability to provide supportive care to the patients was affected by the staff members' personal reactions. They cited several changes which they believed were affecting their ability to cope with their work. These are presented in the next section.

Staff members identified themselves as being affected by multiple deaths. I wondered whether before they could support patients they must resolve their own attitudes towards death, if they have not already done so. They may require assistance in overcoming the



stress of deaths through support groups for example. Kubler-Ross (1973) argues that people are afraid of dying and death. Kutscher (1973) identified caretakers' anxiety about death and their emotional overload by it. The authors above identified the vulnerability of people working in the environment of dying and death. Staff members in this hospice identified the stress created by their work. They felt unsupported in it. Support from the hospice is essential to enable staff members to cope with their work. This step is essential before they offer supportive care to the patients.

The question is what happens when all the dying and multiple deaths upsets hospice ideology. How do patients' sensitivities to the dying and multiple deaths fit into the ideology?

### **Sleep Disruption and Consternation**

Hospital patients were reported by Dunlop and Hockley (1990) as experiencing sleeplessness because of noise and routine turning of patients in wards. The additional attention to death vigils and dying patients and noises made by them could affect some patients' sleep. This was a problem common to communal care. What is not common was sharing wards with dying patients.

Patients described difficulties in sleeping because dying and deaths in wards bothered them. This section explores patients' disrupted sleep and resulting consternation because of dying patients in their wards. In the first data extract, a recent death and the anticipation of another upset this patient:

'I can't stay here. I'm depressed and going down. I've seen a lady die' in my 'room ... I can't go to sleep ... Marilyn was low over the weekend. They called her people in' (0217:6).

This patient was upset by deaths she experienced in the ward. Because the condition of Marilyn, another patient, deteriorated and her relatives were called in as she was expected to die. That and the knowledge of a previous death disturbed this patient.

In the next data extract, a patient shared his dismay about a death:

'I'm not very happy today. A man lying across, died in the night. The same thing happened when I came in three weeks ago. Hope it isn't one of those nights. I had one of the best sleeps last night. Then I guessed when I saw the empty bed. He hadn't survived' (0701:5-7).

The death disturbed this patient when he discovered it in the morning but it didn't disturb his sleep. He was upset and concerned about further deaths and his ability to sleep the night of the death.

Another patient was kept awake by the respiratory difficulties of a fellow ward patient:

P 'Thought the poor man was going to pass away last night. They were all around him. That croaking breathing. Poor bugger. The nurses were sitting with him. When he was sleeping last night, there was something in his throat and he was croaking'.

TM 'Did the croaking keep you awake?'

P 'Oh aye, You couldn't go back to sleep' (0610:4-5).

Although the patient experienced respiratory problems in the ward, he was not moved to a single room. Instead, his room-mate was kept awake by his breathing difficulties.

The patients in this section identified disrupted or potential sleep problems because of deaths and noises made by their dying room-mates.

The last patient discussed her experience:

P One night they began pulling my curtains. It upset me. I thought is 'This my time'. I was so drugged. They told me we thought it would be better if we 'told you in the morning'.

TM 'Who are they?'

P 'The nurses'. They wanted to let me sleep but I couldn't (0509:5).

The patient above was in cubicle 3. The death occurred in bed 2 and these patients shared a curtain. This patient was so drugged that when her room-mate in the next cubicle died during the night and the curtains were drawn on their shared cubicles, she believed that she had died. When she shared this account with me I was horrified. What is it like to believe that you had died? The combination of drugs and curtains set the scene for this patient. Following this incident she could not sleep. The staff did not speak to her about the death until the morning. They wanted to let her sleep but she could not because she was confused and upset by the incident.

The effects of the dying patients and deaths in wards could be seen by the patients to cause difficulties sleeping. They were upset and believed that they would experience difficulty sleeping. Obviously death was on their minds. Thus their experience in hospice included more than their own experiences but events external to them which disrupted and distressed them.

Situations where patients' sleep was disturbed or disrupted by dying fellow patients could have been alleviated if dying patients were moved to single rooms. It was pointed out in the previous chapter that patients with breathing problems met the criteria for single rooms. The question is why these patients were not transferred. The answer is probably that these rooms were not always available in the hospice. Transfers to special rooms Glaser and Strauss (1965) attributed to maintaining closed awareness. They did, however, offer privacy for the dying patient and their family. However, Glaser and Strauss examined these moves in hospitals from the perspective of the individual patient being moved. In the hospice, some moves to single rooms resolved problematic situations in wards. Thus the move was for the collective good of other ward patients and benefited families who desired greater privacy.

### **Responsive Phases to the Dying and Multiple Deaths**

In this section I discuss patients and others whose views were transformed about the hospice because of their experiences with dying and multiple deaths within it. The term responsive phases is mine. Responsive phases were patients' transformed responses about

the meaning of the hospice to them because of situations that they have encountered. There are three responsive phases. Captured in the first phase are people's initial impressions of the hospice. Several engaged in public dialogue to convey their feelings about the hospice. Death, dying and terminal illness were often the theme of the second or third phases. These patients or others had now encountered dying and deaths. Often then, they related other patients' deaths to their imminent death.

The first extracts are taken from a visitor to the hospice:

'They're so kind' and helpful (0321:2).

'He's up and around. I didn't think they brought them in until ...' I guess it depends (0321:2).

They're 'disappearing' I 'saw his' death notice in the paper (0321:2).

This lady in the second data extract, believed that patients were not admitted until they were closer to death and was surprised that a patient was up and about the unit. Then she referred to the death notice of a patient formerly in that ward, recognising that although patients may be mobile about the unit, they also died in these same wards.

In the following excerpts a patient in a side room addressed terminal illness and death in the hospice.

It's great in here. I was scared to 'come in here'. I have 'no qualms' about returning. The nurses are so helpful (0523:6).

Hospice stands for the fact that you have to come to terms with an incurable illness. Hospice stands for the end ... of your life, really. I often think this would be a lovely place, if I wasn't ill. It's a 'nice place', if it's your 'last place' (0603:12).

'Yes, it's a nice room and place, but when you really think about it, it's a place for dying' (0530:7).

Early in this patient's admission, her fears about the hospice were eased by the nurses' helpfulness. In time she recognised that terminal illness and dying were synonymous with the hospice. Although the unit and room were tastefully decorated and luxurious, as she was in a single room, the hospice was a place to die in.

The patient Abbey began by outlining her initial fear on arrival at the hospice:

'I was down when I first came in here, because I thought I was finished. I dreaded coming in here. It's a hospice. That was me finished. I feel different now because everybody is so kind and nice' (0523:9, 0518:8-9).

The nurse ... said, 'you're not going home again' (0520:7).

'Every night in the paper so and so died at .....'. No flowers by request. Donations to the hospice' (0601:4).

Abbey voiced her fears about admission to the hospice. Once again, the caregivers made a difference. She learned that she would not return home again. The reality of that disclosure was captured in the last extract. Abbey equated the hospice with a death notice in a newspaper.

Another patient began by praising the food in the hospice.

I think the food's good here (0231:18).

'They told me that's it ... the cancer is all over' (0221:10).

That young lady died. 'Duncan Stewart'. They're waiting for him to go. They're all going away (0316:1).

When this patient's prognosis was made known to her, she began to panic about all the deaths occurring around her, and that Duncan Stewart would be next to die, recognising her fate would be the same as other patients. Another patient's views of the hospice, comparing it to a hotel, were transformed by her experience with sequences of deaths. She was a young patient:

It's great in here. 'Like a hotel, if you're well enough to enjoy it' (0317:12).

'There've been a lot of people that have died in the last fortnight' (0326:9).

'I said that could be me, that could be me and she died the next morning' (0405:2).

This young patient recognised the deaths on the unit. They became significant for her when another young patient died, as noted in the last data extract.

The last patient's views differ from her initial comments.

'The nurses are gems. They can't do enough' (0518:5).

'You know a lot of people in Britain think', once 'you're in here that's the end of you. They think it's a terminal hospice' (0518:5).

'She died. They never told us' (0603:4).

In the second extract of data, this patient recounted what she believed to be fallacies about the hospice. When a room-mate died, she then realised hospice does mean death. Patients were not told by the nurses about the death of their room-mate.

From these responsive phases we see the superficial image of the hospice versus the reality of it. When literature describes hospice care it does not focus on the dying and multiple deaths which patients witness. These issues were found to be in this study very much on patients' minds and need to be addressed.

### **Competing Priorities and New Conditions**

This section reports the staff's views on why providing supportive care to the patients was challenging. It focuses on hospice ideology and reasons for the apparent failure to meet it. It also illustrates how inappropriate previous care was for alert patients who were upset by multiple deaths. Staff members outlined competing priorities and new conditions on the unit which hindered provision of supportive care for patients. Changes that the staff interviewees identified as affecting hospice care are discussed in this section. They included the types of patients currently admitted, expansion of the unit, previous and present supportive care. By exploring these changes it is possible to understand transformations in the hospice they believed were occurring. Some of the staff members were frustrated by these changes which affected the care they provided. They recognised the necessary supportive requirements for alert patients who witnessed dying as different from those of patients who were closer to death. They



believed the priorities of these two groups of patients must be reassessed. They felt neither group, alert nor dying patients, were consistently supported through their encounters.

Now no time to sit with patients

Support for dying patients was discussed by exploring the hospice's care philosophy with the staff interviewees. In so doing, they revealed what they considered support for patients to be. At present supportive care was inconsistently provided and this concerned some members of staff.

One staff interviewee claimed that the philosophy of care was outlined in the pamphlets distributed by the hospice:

'We are told and it is in the booklets that there will be somebody sitting with them when they die. And these patients are promised that there will be someone' (NA11).

Sitting with dying patients seemed to be a priority for these interviewees. They were frustrated because in practise this occurred less frequently than they desired. Previously, when the inpatient unit was smaller - fifteen beds - staff members sat with patients as they died. According to another interviewee, this practice was no longer ensured:

'No patient will die alone. That's what we were understood to believe it was all about, the hospice, and now, unfortunately they do' (NA1).

Apparently the practice of sitting with dying patients was restricted by busy workloads on the unit.

'Anybody would sit with anyone who is dying'. Only if it is busy then nobody is available to sit with the patient (SN22).

The physical care workload was the priority. Availability of staff was the second factor determining whether they could sit with dying patients:

'The staff nurse or Sister' decides that someone sits with the patient, providing there is enough staff. But now it happens more and more that patients die alone (NA4).

The nurse in charge or Sister decided when staff members remained with dying patients. Sitting with dying patients was dependent upon the availability of staff. However, another staff member identified how sitting with patients was interpreted:

If you're sitting with a patient or a patient 'is dying'. Some here think you're 'skiving' (0404:8-9).

She believed her colleagues viewed sitting with patients as shirking the physical work. Yet this diminishing practice frustrated some members of the staff. Of late, hospice reality seemed to be too busy for placing staff with patients. Still, remaining with patients as they died was considered supportive care.

### Symbolic care

Discussed in this section are the symbolic practices of acknowledging death practised in this hospice. Symbolic care of the dying and dead was foremost in hospice care. It previously included practices such as somebody always remaining with patients as they died, be they relatives or staff members. Another symbolic practice, the empty bed, is included in the next data extract. The discontinuation of these practices, such as staff members sitting with dying patients, was dismaying some members of the nursing staff who were directly involved with patients and their deaths. Staff members previously symbolically acknowledged patients' deaths in the hospice in this way:

We like to keep the bed empty for at least 'twenty-four hours', as a 'mark of respect and for the others' (SR4).

The gesture was seen as intended for patients, their relatives and staff members. The symbolic act was no longer practised. It also delayed the physical workload. Death work and preparing the corpse therefore would not be followed by immediate admission and the necessary work that it involved. A staff member found the discontinued practice upsetting:

It's upsetting when the bed is filled before 'it's even cold, so to speak' (0523:9-10).

The cessation of this practice was one change in hospice care. Longstanding members of the nursing staff were experiencing difficulties in adjusting to this change. These practices may have

been their way of coping with the stress of deaths. The issue is how to handle changed practice and how to adopt appropriate supportive care that incorporates these changes.

'Different type of patient'

The staff members believed that the patient population at the hospice had changed too:

We have a different type of patient. They stay longer. Before they came in and died shortly after. 'They last longer'. It's more 'like a hospital than hospice' (0731:3-4; 0104:6-7).

These were the alert patients who stayed longer and were aware of the hospice environment. During the hospice's early days, patients died soon after admission. Their rapid deterioration and comatose states prevented them from witnessing death, as did Eilish and Sarah, in the cases presented earlier in the chapter. With the changed patient population, the hospice was believed to be more like a hospital.

These patients with extended admissions were referred to as 'geriatric' (NA10) or rather elderly. They were believed to be altering the hospice work. Hospice care became physical care for patients who stayed longer. It was seen to be more 'hospitalised' (NA26).

The 'patients are heavier now'. It's 'physical and emotional. We don't have time to talk to them. We used to when we were in the old place. With only fifteen beds' (0214:6-7).

Since the unit was doubled in size and with admissions of more alert but physically demanding patients, the care was believed to be heavier. Because the staff were busy with physical care, they were unable to talk to patients. They considered talking to be supportive care.

A patient agreed that talk with staff members was limited. She said in reference to talking to nurses, 'The nurses don't have time' (0221:7). Another patient made a similar comment 'that the nurses don't have the time' to talk (0625:3).

#### Current supportive care

Physical and supportive work were seen to be separate tasks causing tension amongst staff members. Routine physical care seemed the priority on the unit, leaving little time for supportive care which was seen as separate from other work. A staff member who took the liberty of sitting with an alert patient, recognised the attention to the physical work:

That's what I'm here for. 'The patients come first'. I realise we need the routines but the trays and baths can wait (0404:9).

She recognised the routines on the unit, as did another member of the staff. 'Individual' care isn't provided but 'routines' are followed (0715:1).

Supportive care seemingly diminished with the increased physical care of patients. Yet these alert patients were attentive and thus

aware of multiple deaths in wards and that these patients died:

Too often now, patients are dying alone. That isn't 'hospice policy'. Nobody is supposed to die alone in here. But many of them do, without their families (0731:3-4).

Once again patients' dying without family or staff members remaining with them was a concern to this person. Tension existed between which group of patients were priority, the dying or alert patients. Staff had to regard the more pronounced physical needs of alert patients. The supportive needs of dying patients and alert patients witnessing the dying also had to be considered. The decision of which group of patients was to be given priority caused tension:

'What I personally feel is you've got to look after those who are still with us. Their priority must come first. Especially, if there are family at the bedside of the dying patient. You've got to think of the other patients, who may be sitting opposite watching. Their comfort comes first' (NA1).

The scene she illustrated was of alert patients witnessing their room-mates dying. They required special attention and support. The hospice staff did recognise patients' fear and agitation because of the deaths they witnessed but beyond this fact no concerted action was taken by them. For example, patients like Eilish and Sarah fit into this category because of the multiple deaths they witnessed. However, they did not receive special supportive care.

The care for dying patients was qualitatively different than that required for alert patients who watched the dying. Dying patients were comatose and unaware of their surroundings, unlike alert patients who were aware of ongoing events in wards. Alert patients' responses to the dying and deaths that they witnessed necessitated supportive care at a level which the hospice staff seemed unwilling or unable to provide.

In this study it was found that the staff believed that they were limited in the supportive care they could provide to patients because of the changed conditions in the hospice. Tension existed between focusing supportive care on dying or alert patients, who witnessed room-mates dying. I question whether the staff desired to confront this issue. This was based on the comments by staff above.

Staff members believed that an increase in physical care required by the patients was the reason that they were unable to provide supportive care, such as sitting with patients or talking to them. Available time to talk with patients was restricted by the increased physical work. Other findings suggest that when more time is available, staff do not spend it with patients. Sitting with dying patients, which the staff believed to be supportive care, occurred infrequently. Only once did I observe a Sister sitting with a dying patient.

From the examples given by the hospice nursing staff and my observations, I could see that physical care was the priority and that supportive care was difficult to establish. I wonder whether

supportive care and confronting the multiple deaths that patients were exposed to was by-passed by claims that the physical care workload was increasing? If we build hospices where physical care is the priority and expose patients to the dying and multiple deaths without tending to them, what have we created? Are patients better off in hospitals where fewer deaths occur?

Routines and competing priorities and new conditions enabled the staff to distance themselves from the patients, if they wanted to. In Wright's (1981) study of a hospice, through various routines the staff distanced themselves from deaths of patients. By distancing themselves in this way, his nurses protected themselves. This counters hospice ideology but allowed the nurses to survive with 'predictable and routine care' (Wright, 1981).

Kubler-Ross (1969) and Feifel (1959), working in the areas of psychiatry and psychology, demonstrated the value in patients' communication about their fears of dying. Though not all patients desire the same levels of communication, this channel should be available to them. In Wright's (1981) study the nurses stated that they talked to patients about their fears. However, he observed very little such talk.

## **Discussion**

In this discussion I will examine patients' and nurses' responses to the repeated exposure to dying and deaths and its relation to hospice ideology. Strategies for handling these responses will also be discussed.



Glaser and Strauss' (1965) and Kubler-Ross' (1970) work with patients' dying in hospitals relates to the care for hospice patients. Glaser and Strauss' awareness contexts dealt with the individual patient coming to an awareness of their dying in a hospital setting. Kubler-Ross outlined the support by staff, through communication, necessary for patients to come to terms with their imminent death. In hospices an open awareness to death is assumed. The frequency of dying and especially multiple deaths makes the hospice unique. Not only must hospice care deal with the individual patient's dying, but also with their witnessing other patients' dying and deaths.

Thus the supportive care necessary from staff, to assist patients, goes beyond dealing with the individual patient's own dying and death and should include the dying and multiple deaths of other patients in the hospice, which goes beyond Kubler-Ross' work. Perhaps hospices have taken on board the idea that multiple deaths were expected and accepted without enough attention to the consequences. Hospice ideology incorporates psychosocial care into its care. Hospice care is sometimes referred to as being holistic, humane and offering dying with dignity. This chapter has exposed some of the fears of dying in a hospice and an apparent lack of supportive care for patients. Field (1989) points out that caring skills for hospital staff must be developed and supported. One of the auxiliaries in this study was a young lady of 17 or 18 years of age, which was atypical of the staff. This development and support it seems, I believe, must come solely from within the institutional hierarchy to support the staff. This young auxiliary would need to be taught caring skills and given support through her

work. These factors are vital in terminal care settings.

Hospice caregivers are vulnerable to the stress of their jobs. In her study of stress for terminal caregivers, Vachon (1987) points out the necessity of team support in working with the dying. Because supportive care is assumed to be delivered in hospices, the effect and stress on patients of others' deaths may not be acted upon. Field (1989) also recognises the stress terminal caregivers face. Hillier (1983) recognises the sadness which staff members may experience at the death of patients. He recommends support of colleagues and senior staff members.

When nurses experienced problems relating to dying patients, James (1986), who studied a continuing care unit, noted that nurses ignored psychosocial care while they focused on physical care. In a hospital Field (1989) found nurses avoided contact with dying patients through task allocation of their work. They used the work as a diversion from psychosocial care. This chapter revealed that preserving order on the unit was crucial to permit 'getting through the work' which Melia (1981) and May (1990, 1991) recognised in their research. Despite the area of nursing, completing the physical care is seemingly the priority.

I argue this is what occurred in this hospice. Physical care was the route through which nurses by-passed the supportive care. I argue, however, that hospice patients' exposure to multiple deaths without them being discussed may be harmful to patients and is far from enabling their dignified dying. Sitting with dying patients, as a supportive measure, may have been successful when patients

were closer to death, but is presently inappropriate in the changed circumstances with alert and MND patients. The double standard in this hospice was noted where the staff member stated that she would want to leave the hospice, if she were in a ward where patients were dying around her, is telling. Moreover, her response to a patient saying to her that the patients were all dying like flies - to leave the room - suggested an awareness of the multiple deaths, but an unwillingness to confront the issue. Promptly informing ward patients and their relatives when deaths occur was proposed by O'Brien and Monroe (1990). It is an initial step in confronting deaths that would contribute to supportive care but only if followed up with support and opportunities for patients to talk.

Hinton (1972) addressed anxiety and depression in terminally ill patients in hospital. He revealed how stress and death are linked. He believed that a relationship between stress and death is possible when physical health conditions are unstable. He noted that progression of diseases alone may contribute to patients' anxiety, although no common trend was identifiable. Hinton's data was obtained from general hospitals. Thirteen per cent of patients dying in general hospitals were found to be anxious. Twenty-five per cent experienced apprehensions and vacillating bouts of fear. Younger people were more prone to anxiety. Depression occurred when illnesses were protracted and when physical discomfort was present. This generally is not a consideration in hospices as pain control is a priority of care. Thus establishing the root cause of patients' anxiety and depression was related to the physical disease process. Hinton noted that when patients with similar diseases shared wards, they displaced their anxiety on their room-

mates. However, in Hinton's study, patients did not necessarily share wards with patients with terminal diseases. Hinton noted that 'psychological stress can apparently precipitate death in patients in a precarious state of health' (p:92). These factors need to be considered in relation to the dying and multiple deaths that these hospice patients witnessed.

I believe that we must look at the increased anxiety which patients in this study were exposed to because of the multiple deaths they experienced. Anxiety and depression are issues in their own right. Their relationship to multiple deaths may or may not exist. In the responsive phases in this chapter, the patients compared themselves with other patients close to death or dead and this realisation disturbed them. The fate of the dying and dead patients would soon be theirs. This caused panic in some patients. The witnessing of dying in this hospice was intended to be helpful to patients in accepting their imminent death. However, it meant that some patients were forced to witness dying. Their coming to terms with death was not on their own time or terms, but imposed on them because of what they witnessed. Witnessing others' dying or awareness of their deaths was also a feature of the responsive phases. Wright (1981) argues in his hospice study that, by witnessing rehearsals of their own death, patients can gauge their progression through dying. This is a positive aspect. It indicates that hospice ideology recognises multiple deaths. It may, however, be dependent upon input from the nursing staff to guide patients through these experiences with death. The third phase of the responsive phases revealed that dying, death and terminal illness were talked about in relation to the deaths of

fellow patients.

This chapter revealed that patients were affected by the dying and multiple deaths they witnessed and the action taken or not taken by the staff. Data also suggested that the staff were bothered by the multiple deaths which may have prevented them from supporting patients. Hospice ideology intended to provide psychosocial care, but this ideology and care was shown to be tested by the dying and multiple deaths. Hospice ideology was developed in the past and changes have occurred over the years, including perhaps the types of patients admitted to hospices, who were affected by what they witnessed. How helpful were these events to patients during their last days?

## CHAPTER 8

### DISCUSSION

## Introduction

Death and dying in traditional health care settings have been seen to be problematic. My intention was to investigate how terminal care was handled in a hospice setting. In this study I set out to explore patients' views of their experiences with death and dying. Input from relatives was included because they provided supplementary information, especially when patients became comatose. The staff members' views were a corroborative data source. These actors' perspectives provided a multi-dimensional picture of the management of dying and death in the research site. In this thesis I set out to explore several questions. How are dying and death managed in the hospice setting? How do patients discover the occurrence of death? How do patients feel and react to the dying and deaths they encounter and what are their views about them? The sensitising concept guided the development of the research questions and the fieldwork.

Three themes were developed from the data as outlined in Chapters 5, 6 and 7; namely, 'concealing death', 'displaying dying' and 'responding to dying and multiple deaths'. Their disentanglement, inter-relation and subsequent integration were challenging. 'Displaying dying' is the core theme in this thesis. It evolved from the sensitising concept of an 'openness to death'. Because death was illustrated to be concealed, 'displaying dying' exemplifies how hospice care was managed. In this chapter I discuss the central theme of 'displaying dying', as it is related to the other two themes and explore how it related to dying and death in this hospice. In the course of this discussion the

relationship to the other themes becomes obvious.

### The Evolution of the Sensitising Concept

The sensitising concept of an 'openness to death' was derived and developed from the literature on the hospice movement. It suggested that the death taboo did not operate in hospices, whereas, in other health care institutions, it persists. 'Openness to death' seemed a possible reason for the alleged success of hospice care that is promoted in the literature on and by the hospice movement. In this section I discuss the evolution of the sensitising concept from the start of the fieldwork to its completion.

The success of hospice care, or so I initially believed, was linked to the sensitising concept and because patient care was provided in the communal environment of wards. Exploring whether and how this relationship functioned was an objective of the fieldwork. As the fieldwork progressed, my belief about the relationship of these two factors became one of ambivalence.

The discovery that death was concealed, wherever possible, raised questions that challenged my sensitising concept. In the hospice, caregivers were said to provide unique care, but it took time to discover what was unique about it. Deaths in wards offered an angle from which to explore patient care. In the course of that exploration, it became apparent that death and dying were viewed, and were managed, differently. Dying was displayed whereas death was concealed.



Initial comments from newcomers to the hospice were positive. They were impressed by and enthusiastic about the approach they were confronted with. Undoubtedly their views were influenced by the decor, provision of tea and cakes, flowers everywhere and the pleasantness of the staff and volunteers. Later on, and when relationships were established with these people, some patients and relatives spoke more negatively about aspects of hospice care. They mentioned the busyness of the staff and their distress caused by the dying and deaths that they witnessed.

The advantages and disadvantages of communal terminal care left me ambivalent about ward-based terminal care. The benefits of communal wards contributed towards opportunities for companionship between patients who could share their experience and that of others. Alternatively, communal care, and its resultant noises and disruptions because of the dying, often disturbed patients, for example by affecting their sleep, which was illustrated in Chapter 7. This problem of communal care has, however, its specific repercussions in hospice care. Alert hospice patients were involuntarily exposed to the dying of their room-mates. This exposure was a deliberate hospice objective, deterioration and dying intended to assist patients to come to terms with death and dying. However, it also induced upset in some patients as was illustrated in Chapter 7. The objective of displaying dying was altruistic: i.e. for the benefit of ward patients. However, it was imposed on patients, impeded privacy and sometimes it could be seen as detrimental to their well-being. Furthermore it impacted on the well-being of visitors who, themselves, had their own emotions to cope with. Emotional responses in patients and their

visitors proved to be problematic for the staff.

The sensitising concept of 'openness to death' developed from the data into three themes: 'concealing death', 'displaying dying' and 'responding to dying and multiple deaths'. The themes highlighted patients' experiences and views. The question now is whether death and dying were treated openly in the research site? I argue that 'displaying dying' contributed towards a greater openness towards the process of dying. The data also revealed, however, that, whenever possible, death was managed so as to be downplayed or concealed. 'Displaying dying' came closest to illustrating the sensitising concept. Staff were clearly intent on trying to conceal situations in which dying was distressing rather than peaceful. Thus, in fact, the sensitising concept developed from 'openness to death' to openness to dying. Dying was 'selectively' displayed and only what was intended by staff to be witnessed in wards was made public, as has been shown.

### **'Displaying Dying'**

In the following sections I discuss the theme 'displaying dying' which, I now argue, is central to the management of patients in the hospice. This discussion illustrates how 'displaying dying' was a performance in which staff, patients and relatives participated and what it apparently achieved.

The objective of care in open wards was supposed to be for the benefit of other patients so that they could see what death was like. However, because death was, whenever possible, concealed, it

was dying therefore that patients actually observed. Dying was displayed to patients, relatives and visitors.

### The performance

Life is a performance, argues Goffman (1959) and most performances are orchestrated to conceal certain facts from people. Goffman continues that performances occur in the 'front stage' and the 'back stage'. The main performance, which is intended to be observed, occurs in the front stage, while the back stage contained those events which were not meant to be witnessed in public.

In this thesis I argue that 'displaying dying' was the main performance. It attempted to portray the image that dying was a peaceful process. Wards were the 'front stage' and patients and events within them were intended to be observed openly. The 'back stage' in the hospice was the siderooms. They concealed patients whose dying was problematic and they were used for various reasons that were identified in Chapter 6. What hospice staff wanted to be witnessed was displayed in wards.

Denzin (1983) supports Goffman's claims about performances and continues by describing characteristics of these performances. Denzin suggests that people express themselves in personal ways through interactions. He calls this characteristic behaviour 'behavioural repertoires'. They occur in locales like public or private spaces, during sacred or secular occasions like death. Here special language is used and characteristic behaviours can be observed.

Denzin's identification of language and behaviour were observed in this study. Dying occurred both in public and in private - in wards and in siderooms. Dying and death are often understood as sacred events. Death vigils can be interpreted as parts of such events. Events or symbolic objects control people because meaning and appropriate behaviour are shared. The mutual knowledge about them provides a controlling element. These were what Sites (1973) referred to as 'symbolic tactics'. Death vigils represented symbolic associations to dying and death that was shared. Ward room-mates respected death vigils and shared the meaning of the event generally by responding with quiet behaviour. Still, in extreme cases, other patients were disturbed by the death vigils, if relatives displayed uncontrolled emotions.

Public and private dialogue as used in the hospice fulfilled Denzin's criterion of special language. Public dialogue assisted people in their conversations. It contained topics that could be discussed openly in the hospice environment, if people were uneasy about appropriate conversation. Private dialogue consisted of language that was metaphorical and sometimes crude, to describe more unpleasant events in the hospice. It referred to certain work tasks and aspects of patients' conditions; and it was generally only used by the staff. At times, though, distraught patients used private dialogue to convey their distress.

The work of staff members, especially of 'displaying dying', bears similarities to funeral directors' work. Both arrange performances in similar ways. In his study of funeral homes, Barley (1983) describes how funeral directors 'arranged cues or created signs to

mitigate those perceptions of death that might upset people' (p:402). Because the sight of a body could cause unpredictable behaviour, funeral directors sought to create the appearance of normality or naturalness when people were in the presence of a body.

'Displaying dying' involved staff arranging dying that which was meant to be observed and that which was intended to be concealed. Thus the dying was sometimes staged in a similar way to the work of funeral directors.

#### Socialisation, sensitisation and control

What 'displaying dying' achieved and how it was achieved are now discussed. Socialisation refers to integration of the actor, engaging in appropriate behaviour and normalising particular experiences. If people were nervous about visiting the hospice, they were assisted towards socialisation by the hospice decor and the interactions of staff members with dying patients. The pastel coloured walls, plants and furniture provided a soothing atmosphere. The decor also provided initial topics for their conversations. People contrasted it with the decor in other institutions and were amazed by the differences. Goffman (1963) noted how individuals in social situations incorporated others' presence and behaviour into their own behaviour. He identified that decor influenced behaviour because it 'tends to fix a kind of spell'. Barley (1983) argues that decor is an important factor in funeral homes because it attempted to portray a home-like atmosphere and it could relax people.

Another outcome of 'displaying dying' was sensitisation to dying. This was achieved because patients were placed together in wards and therefore could observe each other. Patients were sensitised to the sights of dying. Visitors, as observers, benefited in a similar way. The aim of prolonged exposure to stimuli such as dying was to reduce negative responses to it. Desensitisation was successful when patients became immune to the deterioration of their room-mates' conditions. Desensitisation, Zimbardo and Ebbesen (1969) argue, is an element of social control.

'Displaying dying' was assisted by transferring problematic patients out of public view to siderooms. Thus 'displaying dying' was at times a sanitised performance which removed problematic patients or intended to resolve problematic situations. When the dying became noisy, unsightly or smelly, a patient could be moved to the back stage, i.e. a sideroom, and out of sight. These transfers prevented ward room-mates from observing the late stages of deterioration. Transfers to siderooms were a control mechanism that redressed disorder or potential disorder in wards and neutralised what events were witnessed by patients. Placing problematic dying patients in the back stage may have eased the work and stress for staff because they would have fewer people to explain a death to because they would be less public. When transfers were impeded, the dying patients sometimes disrupted order in the wards and their room-mates were adversely affected by it.

Social control is the basis for establishing order, Silverman (1970) argues. Further, he contends that its advancement depended

upon co-operation between people to present a uniform version of reality. Uncertainties in situations arise, Berger and Luckmann (1967) point out, which are not routinised and therefore social order itself was problematic. Despite the efforts by the hospice staff to maintain order on the unit, order was affected by the uncertainties in terminal illness and patients' responses to events. Sites (1973) identified and defined manipulative strategies as those which control behaviour. Manipulative strategies can be non-verbal or verbal. Socialisation and social control are the extremes within the spectrum, although socialisation is a normal occurrence. Non-verbal manipulative strategies that the staff used were displaying the dying, transfers and death concealment strategies. Public dialogue was also an effective verbal manipulative strategy because it also controlled behaviour.

Because of the religious symbolism of death vigils, they too seemed to control behaviour. This occurred when room-mates observed death vigils while people in death vigils observed room-mates. This had a controlling effect on all people's behaviour in wards. For instance relatives alerted the staff if the condition of the patient changed, for whom the death vigil was being held. Thus staff could attend to other tasks while death vigils were ongoing. Death vigils played a significant role in socialising, sensitising and controlling behaviour.

The benefit of keeping death vigils in wards was, it can be argued, that they socialised and controlled behaviour. However, not all participants in death vigils were willingly present in wards. Some



relatives desired privacy. The hospice staff could prevent relatives from obtaining privacy during death vigils. Hospice staff members sometimes withheld the fact that siderooms were available in the hospice. This decreased the relatives' requests of staff members for these rooms. Thus relatives' wishes for privacy during death vigils conflicted with the hospice image of sharing experiences and they were subjugated to control by the staff. Berger and Luckmann (1967) addressed social order in the world and that it is fixed and imposed upon people. Withholding information is a form of social control (Sites, 1973). By displaying dying in wards, the staff imposed some control over people and situations.

The hospice ideology was intended to remove the death taboo. 'Displaying dying', however, indicated movement shifting towards eradicating the death taboo through greater openness towards dying. 'Displaying dying' in wards was both helpful and problematic for patients, relatives and staff alike. It socialised, sensitised and controlled patients and their visitors. The concealment of death in the research site, however, reflected that the taboo persisted.

### **Patients' Emotional Responses**

Patients' emotional responses to events they witnessed in wards are discussed in this section because they identify the disadvantages of open wards and observing dying and being exposed to multiple deaths. I argue that the combination of exogenous factors, such as ongoing dying and multiple deaths, and endogenous factors, such as hospice patients coming to terms with their imminent death, were



detrimental to their psychological well-being.

The influence of endogenous factors on on patients' conditions were not explored directly in the fieldwork. However, because it could be argued that they were a contributing factor to patients' distress, they are now being considered in this discussion. My argument, however, focuses on the exogenous factor.

### Exogenous factors

At some point, witnessing dying and multiple deaths appeared to influence some alert patients' behaviour. Their emotional responses to these events revealed weaknesses in hospice ideology of open wards, that lead to questions whether patients were supported through their experiences in wards.

One patient was kept awake by the 'croaking noises' his dying roommate made. What were his thoughts as he lay in bed and listened to the noise? Were the staff unaware that other patients might be disturbed by the noises being made? When the nurses pulled the screens around the bed of a patient who had died, the patient in the neighbouring cubicle, who shared the same screen, believed that she had died. She was greatly distressed by this experience. These situations were presented in Chapter 7. The staff management of the second situation must be questioned. The patient understood that the nurses believed she was asleep when this incident occurred. Were the nurses not aware that patients may have been awakened by the noise and wondered what had happened? The patient stated that she was too upset by the event to sleep. She would

have needed support at that time. She related these details to me well after her neighbour's death and this reflected the impact of the event on her because, until this time, little contact had been established between us. Did that event influence the remainder of her life, and how so? The nurse's priority in that situation was probably the work of removing the corpse and laying out the body. The priority probably was attending to the work created by the corpse, rather than the shocked fellow patient, whom the staff may or may not have been aware of. In Sarah's case, presented in Chapter 7, the occurrence of patients 'dying like flies' overwhelmed her. She spoke at length about how upsetting it was watching the dying and multiple deaths around her.

When patients responded emotionally to dying and multiple deaths, their responses challenged the staff who handled these responses indirectly through work strategies of transfers between rooms, death vigils and death concealment or by downplaying, delaying or ignoring them. Patients were left to deal with the distress themselves. I argue that the hospice exposed patients to situations they might not choose to encounter, given prior knowledge of events that transpired within the wards.

When actors act in unexpected ways or unexpected situations arise, Goffman (1959) argues, social order collapses. If the staff continued with their work and believed that the patients were unaffected by the dying and multiple deaths, then social order was superficially maintained. If staff probed deeper into patients' emotional responses, then social order could collapse and require supportive intervention from them. Munley (1983) argues that

witnessing dying and death distressed hospice patients and that they mourned the loss while they were coming to terms with their own death. This was my experience too.

In Eilish's case, described in Chapter 7, her transfer from a ward where multiple deaths were occurring was successful until death occurred in the second ward. Then her distress returned. The problem remained and was unalleviated by the transfer. The 'problem' was her response to death. This was an ongoing problem that patients with Motor Neurone Disease, such as Eilish, or other alert patients encountered in the hospice because their admissions were protracted.

The work strategies which the staff engaged in for managing dying and death prevented patients from showing their upset caused by seeing others dying. This limited the emotional work for the staff, although the effect of these work strategies could not be guaranteed to successfully detract patients from witnessing the dying and deaths. Corpse removals and sealing the unit attempted to contain what patients observed. Corpse removals from siderooms resulted in fewer people witnessing this. They were not always successful as the case of 'The procedure in disarray' in Chapter 5 illustrated. Another study revealed a different strategy that assisted nurses during corpse removals. In the hospice which Wright (1981) studied, bodies remained behind closed cubicle screens until night-time. Fewer patients then observed the procedure.

### Endogenous factors

Now the influence of endogenous factors are explored. Perakyla (1989) identified that hospital nurses compartmentalised care of dying patients by categorising it into four frames: the practical frame of death, biomedical, lay and psychological frames. I focus on the psychological frame because it relates to patients' emotional responses in this study. Perakyla found that when dying patients deviated from their expected psychological identity, it threatened the working conditions for the staff. This deviation led to anxious patients. The staff interpreted and managed the situations through an 'awareness of death, repression of feelings, denial of death, acting out one's anger. Thus death means emotional and cognitive processes which can be identified, controlled and managed' (p:118). Patients' reactions were attributed to their anxiety and the onus was on them to solve the problem. The staff believed if they gave in to the patient, other patients would make similar demands.

Patients' anxiety in Perakyla's study was attributed to their coming to terms with death. However, I believe that witnessing dying and exposure to multiple deaths, contributed to or triggered patients' emotional responses and added to their anxiety. Wilson (1985) argued that dying patients' emotional needs were more stressful than their physical needs. Two studies pointed to the influence between endogenous factors and anxiety. A link between stress and patients' impending death was identified by Hinton (1972). He noted that the progression of disease alone contributed to terminal patients' anxiety. McGuire (1983) found that

terminally ill hospital patients dealt with their prognosis alone. He identified that between a quarter and a third of cancer patients developed anxiety states and/or depressive illness and that 80 per cent of this psychiatric morbidity was unrecognised and untreated.

Psychotherapy for hospice patients, Hayslip and Leon (1992) argued, was beneficial for hospice patients, despite their prognosis. If psychiatric morbidity was undiagnosed and untreated in hospice patients, they could benefit from the services of a psychiatrist and from appropriate medication. Howarth (1981) noted that hospice patients benefited from the services of a psychiatrist on the staff. No psychiatry services were available in the research site where the present study was carried out. A psychiatrist or counsellor in the reserach site, who confronted the issues distressing patients, may have been beneficial to patients and staff alike.

Kubler-Ross (1969) encouraged the idea of allowing patients to come to terms with death in their own time. This was impeded in this hospice with ongoing dying and multiple deaths. They were a source of stimuli and evident anxiety for the patients. Therefore, patients undertaking the emotional work of coming to terms with their death at their own pace, was problematic without support from the staff.

What is realistic to expect the hospice staff to attempt to achieve? In the research site death and dying situations were managed by the staff's work strategies, although they were not always operational and successful because of the lack of available

siderooms and wards for transfers. Emotional care in this hospice was inconsistent and unco-ordinated. Rather than confronting patients' distress through their work, the staff attempted to control what patients' witnessed, delayed or evaded communication or ignored their distress. These strategies manipulated events but did not resolve the problem of patients' emotional responses to their experiences. Improved communication and psychosocial care are possible interventions. These fall within the domain of 'care' that James (1986) identified, which are discussed later in the chapter, as being difficult for nurses.

Sudnow (1967) described nursing care in hospitals that involved dying and death. He concluded that, even with developed routines to deal with the dying and death, staff were vulnerable to the dying and death.

The question is whether the staff in the hospice under study desired to confront the issue of patients' distress. I believe that the hospice staff were also upset themselves by multiple deaths which hindered the care they provided. Without support for themselves, perhaps they were unable to provide support for their patients.

#### Care in Wards?

The hospice concept cares for patients of varying stages of terminal illness together in open wards. Hospices offer palliative, respite, supportive and terminal care to patients (Lack, 1978). Patients' needs, care and levels of consciousness,

which ranged from alert to comatose states, varied. It was the alert patients in this study who were aware of the dying and multiple deaths and who appeared to suffer from the inevitable distress of witnessing these events in open wards.

In this thesis, however, some advantages of ward care were identified. They contributed towards patients' and others' socialisation and sensitisation to dying. Thoreen (1983) argued that wards enabled patients to support each other because they shared experiences.

But because of the data collected in this study, I am ambivalent about the appropriateness of open wards. Here problems occur for patients which were inconsistently acted upon by the staff. Authors differ in their views of whether patients were aware of the dying and deaths in hospice wards and the implications thereof. Care in hospice wards is a controversial issue:

'The herding together of those soon to die is an unattractive concept, justified because in fact it works surprisingly well' (Wilkes, 1981).

'... some feel strongly that no patient should be expected to witness the death of another person dying in the same room or bay' (Saunders, 1984).

'... but can we in our more rational moments support all or any of the tenets of the hospice movement: that collective dying is a good thing and that terminal care is to be separated from all previous care of the sick? Collective terminal care, however humanely tailored, is still collective. Are they really helped by the proximity of three or four or half a dozen others, each also dying? And what does the collectivisation of death do for staff?' (Douglas, 1991:74).



At least three studies conducted in hospices provide evidence of the fact of hospice patients' awareness of dying and deaths in wards and that patients responded adversely to them. Admittedly the focus of these studies dealt with issues more extensive than dying and deaths in hospices. Lugton (1986) found in the hospice she studied that patients were aware of the dying and deaths and that their relatives believed that they were disturbed by them. So did the hospice patients that McDonnell (1987) interviewed. She found that patients were upset by the dying they witnessed. Munley (1983) noted that hospice patients were sensitive to the deterioration of patients around them. She argued that observing dying patients, or a mortician transferring a body, produced anxiety in patients. It triggered thoughts about their own death.

Parkes (1979), however, found that over half the hospice patients he studied were unaware of other patients' deaths in their wards. Apart from that of Parkes, other studies support my observations that patients were aware of, and some were distressed by, the dying and multiple deaths they witnessed. Munley clearly linked patients' anxiety with the deaths and dying patients observed.

This thesis and the above-mentioned studies underpin that alert patients are sensitive to the dying and deaths occurring in wards. Hospice philosophy offers care in a communal environment. Care in a communal environment has been shown to be problematic because of the adverse effects to patients, despite strategies used to alleviate these situations. Either more effective psychosocial support for patients and staff is provided, or the management of terminal care in communal situations should be disbanded.



## Hospice Caregivers' Work Strategies

This section focuses on how work strategies were the primary focus in the hospice chosen for the present study, rather than patients' needs. Other studies support this view and illustrate how other forms of care are displaced by the work strategies.

Communication with patients seemed to be secondary to the practical work of patient care in this hospice. The staff members in the research site claimed themselves that communication with patients was limited. This claim was substantiated by patients who stated that staff were too busy to talk to them. However, the data also revealed that communication about death was limited, delayed, whispered or absent. Patients were not routinely told about roommates' deaths. The theme of 'concealing death' illustrated that communication about death was selective and controlled. It was illustrated in Chapter 5 that no communication occurred with patients before their screens were closed for a corpse removal, although the hospice policy recommended it. These strategies employed by the staff seemed to attempt to control situations and to emphasise practical tasks rather than supporting patients through these events.

Sites (1973) argued that support and control strategies demand different skills and Cumming (1968) argued that support and control required different skills and that tension existed between them. The hospice staff focused on controlling who witnessed the corpse, rather than communicating with patients about what had happened and informing them of the staff's plans for removing the body. They

focused on the work strategies of the corpse removal, and especially on concealing it, rather than on the care and support for room-mates.

Focusing on nursing work is a means of diverting attention from communication and other researchers have identified this as a common strategy in nursing. Knight and Field (1981) and Wegman (1979) found that task allocation on an acute ward was an effective means of evading questions from patients. Thompson (1978) examined ethical issues in terminal care and he noted that the busyness of nurses was often deliberate, with the objective of avoiding forming close relationships with patients.

'Care' and 'work' can be separated according to James (1986). She pointed out that each hospice differed as to its 'priorities for balancing care and work'. She noted that when nurses experienced problems relating to dying patients, they ignored psychosocial care. They left the emotional work to the nursing auxiliaries. The nurses focused on the physical care. The priority in my study seemed to be the work rather than care, using James' distinction. This may have been the staff's means of coping in this undoubtedly stressful environment. In another study, hospice nurses relied on defence mechanisms to limit close involvement with patients (Lugton, 1986). These mechanisms, such as avoidance, safeguarded staff from the stress of emotional involvement with patients. Turner (1987) argued that, through routine activities, individuals ritualised interaction. It distanced the 'interpersonal' work. Whether work strategies for diverting from other forms of care are intentional, and why this may be so, will be discussed later in the

next section, as will be hospice staff's need for support.

### **Dying, Deaths and Support for Staff**

The dying and frequency of deaths will be a continual source of stress for the staff members. Multiple deaths were shown in Chapter 7 to affect some patients. In this section the influence of these deaths on staff members and support for them through these situations is explored.

Munley (1983) pointed out that multiple deaths may be a source of stress for hospice nurses and that their grieving was multiple too. Also, according to Millet (1979), nurses were emotionally affected by patients' deaths. Vachon (1986) identified terminal caregivers' repeated exposure to deaths and suffering, and referred to it as 'battle fatigue'. Battle fatigue included symptoms similar to 'burnout'. Vachon (1987) linked communication difficulties with patients and relatives, co-workers and hospice administrators as contributing to burnout. Burnout can be experienced by an individual or within a system (Edelwich & Brodsky, 1980; Vachon, 1987). It seems that both the hospice staff and the research site experienced burnout. Kastenbaum (1978) argued that hospice staff were susceptible to 'bereavement overload' which resulted from an inability or lack of opportunity to work through the feelings of patients' deaths.

The need for formal support of hospice caregivers is now explored. This section begins by illustrating how two staff members responded to the hypothetical issue of multiple deaths as they related to

patients and themselves. It suggests the difficulties for staff in providing supportive care to patients, when they themselves were affected by multiple deaths. They were asked how they would respond if a patient said to them, 'they're just dying like flies'. This data was previously presented in Chapter 7. The first experienced staff member responded:

'Well I would but I would just say well, they all, they've come in very ill and that. That's a difficult one isn't it, really? Most of them know they are coming into a hospice. They are going to die but, if you say, when they say that, it means that there's been more than, just one or two in the ward. So it means that there're. Big concentration of deaths around them. I just really don't know quite how I would answer that one to them' (NA1).

Another more junior staff member was more certain of the action she would take if patients spoke about multiple deaths to her:

'I wouldn't say a word to them. I'd turn and walk away' (NA29).

She was then asked how she would react if she were in the patient's position, with deaths occurring around her:

'I'd have the screaming adabs. I'd want to go home. I think it would be very depressing' (NA29).

The first staff member was uncertain of the action she would take; the second knew the action she would take. Her reaction, if the tables were turned, revealed a double standard. More important, the first data extract suggests that discussion with patients about multiple deaths did not occur. It was surprising that the more

experienced staff member, during her many years of employment with the hospice, had not encountered patients who had discussed multiple deaths with her. Yet patients initiated such discussions with me. The data quoted above also illustrate that several times during the fieldwork, multiple death situations were difficult for the staff. It also suggests that the skills of communication and counselling skills of staff were limited.

Field (1989) argued that caring skills, for nurses working with dying patients in hospitals, must be developed and supported. The same is required in hospice care. What counselling skills were taught to new staff members during their training? The hospice offers bereavement counselling to relatives. This same facility did not seem available to patients faced with multiple deaths of their room-mates nor to staff who also experienced these events.

The issue of whether a formal support group existed for unit staff members was raised with a hospice administrator. That administrator had previously led such a group which was no longer operational. The reason given for the demise of the group was that staff members were raising personal issues which related to their personal lives. The administrator felt these issues were inappropriate. The question is whether the administrator was an appropriate person to lead the group.

During the fieldwork a mixed support group was initiated by a Home Care nurse for workers in the hospice. It was poorly attended by the nursing staff. A senior nurse believed that the staff were reluctant to discuss the dying and deaths on the unit with the

hospice volunteers who were naive about the practicalities of the unit staff's work. The staff members' supportive needs probably differed from those of the hospice volunteers. One staff member openly addressed the lack of support for the staff through the multiple deaths they encountered. Grief is an emotion that terminal caregivers are susceptible to, according to Murray Parkes (1979, 1986). He recommended support for the staff members through regular group meetings.

Vachon et al (1978) studied nurses working in palliative care units. They found that nurses' 'stress scores' were twice as high as those in a control group. The scores were then compared with women beginning radiotherapy for cancer of the breast. The nurses' stress levels were shown to be higher than those of these patients.

Support must be built into team care but cannot occur without the assistance of the administration. Staff support from the administrators in the research site seemed to be weak. One of the hospice administrators stated that, if staff members accepted the job, they must cope with the demands of it. It is, however, essential that support is available for the hospice staff because of the bereavements they encountered (Saunders & Baines, 1989).

The services of a psychiatrist could be considered because that person could provide support for the caregivers as well as tend to the psychosocial functioning of the patient and their family (Hayslip & Leon, 1992). Conby-Hill (1986) argued that stress management should be available to people working with the dying. Weisman (1988) believed that maintaining the morale of staff

members is a key element in hospice care. Possible options to deal with hospice caregivers' stress have been outlined in this section.

### **Further Considerations**

During the past several decades the growth of the hospice movement has flourished and continued to do so. Hospice care is believed, at least by some, to provide 'better' terminal care than hospitals. This discussion questions the claims about hospice care, although, admittedly, this study did not seek to compare hospice and hospital care.

The sensitising concept of 'openness to death' evolved into the theme of 'displaying dying' and how 'concealing death' and 'responding to dying and multiple deaths' related to it. 'Displaying dying' suggested that a greater openness to dying in the hospice existed. Death, however, was concealed whenever possible and thus the death taboo prevailed in the hospice.

Munley (1983) distinguished hospices between being 'death houses' or places where people can 'live as fully as possible until they die' (p:136). Certainly if hospices were publicly recognised as 'death houses' that could deter admissions and/or create fear. Thus, presenting a positive image to the public is essential if hospices are to survive. Silverman (1970) argues that the necessity of organisations, in obtaining resources from society to obtain a market for their 'output', results in converting people to their cause. Since people present an image to others, it follows that the hospice presents an image to the public. I have shown



that dying and deaths were ongoing in this hospice and the performance of 'displaying dying' attempted to portray these events as being peaceful. The benefits of 'displaying dying', for patients, visitors and staff, have been noted. The disadvantages were that patients' responses to the events they witnessed were not always effectively dealt with.

The claims about hospice care are furnished through rhetoric such as 'quality of life', 'quality of care' and 'dying with dignity'. These terms are now explored. Hospices attempt to provide 'quality of life' for patients which Hayslip and Leon (1992) identified as touching on many aspects. Quality of life, Mahoney (1986) pointed out, was subjective and a personal opinion, like dignified dying, therefore, another person cannot establish the quality of other people's lives. Fowlie et al (1989) argued that it was difficult to define and measure the quality of terminally ill patients' lives. They believed that, when exploring quality of life, the following factors must be considered: the person's past experiences, their support system, the degree to which the person is at peace with themselves, their involvement in the treatment and care and the effectiveness of symptom relief provided. These factors illustrate the complexity of measuring quality of life in the case of terminally ill patients.

Hospice leaders, Abel (1986) asserted, tended to exaggerate the influence of hospice care. Quality of care encompassed (i) symptom relief; (ii) social, practical and emotional needs; and (iii) adequate communication, and Higginson and McCarthy (1989) argued that it has not been proven that hospices consistently provide high



quality of care. Kane et al (1984) found no differences in symptom control between hospices and hospitals. Mahoney (1986) argued that 'hospice care, quite honestly, is probably not the panacea that some in the hospice community would insist it is' (p:15). He specified that the quality of life of patients close to death differed from the quality of patients further from death. He identified the same point that I made regarding alert and comatose patients. The quality of alert patients' lives could be adversely affected by events they witnessed which a comatose patient would not. Kastenbaum and Aisenberg (1972) noted that dying patients experienced sorrow in grieving for themselves. This was often accompanied by depression.

'Dying with dignity' is said to be synonymous with hospice care (Munley, 1983). The term is open to interpretation. What does it mean? How can it be measured, given the deterioration inherent in terminal conditions? I believe that some patients in this study experienced undignified events. Further to this point, these events may have adversely affected the remainder of their lives.

Quality of life, quality of care and dying with dignity are more complex and controversial issues than the rhetoric suggests. They do, however, provide a positive image of hospices to the public.

Have hospices set objectives which they are incapable of achieving? Cicely Saunders (1991) referred to 'inbred beliefs' about hospice care and recommended a 'sacred cow shoot', if necessary, to improve hospice care (p:187). Hospice care is also being questioned by several researchers, as to whether its ideals have been achieved

(Abel, 1986; James, 1986; Seale, 1989). Whether hospice care is actually beneficial has not been completely established, claimed Weisman (1988). Hospice care may not be unique to hospices and Abel and Seale support the view that it may resemble hospital care. Seale recommended a thorough evaluation of hospices. Abel argued that assessing the impact of hospice care was difficult. Small research projects are being conducted in independent and NHS hospice-type units but an evaluative, nation-wide study has not been undertaken. Further research is necessary to compare terminal care within hospices and between hospitals.

Whether and how the hospice patient population has changed over the past thirty years needs to be established. If the alert patients that I found in this study are similar to geriatric patients, their care and accommodation may need to be reassessed. In this thesis I am questioning the appropriateness of care in wards because of what it exposed patients to, especially alert and MND patients because of their protracted admissions. Should alert and comatose patients be placed in the same wards? Co-ordinated support for patients through their distress seemed weak. So too was the support the staff members received in meeting the objectives of their work. Further designers of hospices might wish to consider which types of hospice units are most effective and whether the emphasis on wards is the best way forward. These decisions can only be taken after a more comprehensive study of hospice care has been undertaken.

The hospice movement challenged the death taboo. This study began by exploring an 'openness to death' and found that death was concealed but that dying was displayed. Thus a greater openness to

dying existed, but it created problems for alert patients. More importantly, though, patients responded emotionally to the dying and multiple deaths they witnessed in the wards of the hospice.

The following plea from a patient is an element of hospice care that cannot be ignored:

'They're disappearing ... Dying off ... Ah, that's so depressing. Every time you look up one's away. They're just dying like flies' (0312:15-18).

**APPENDICES**

APPENDIX I

Letter to Hospice Administrators for Negotiating Access

Nursing Research Unit  
12 Buccleuch Place  
Edinburgh EH8 9JT

Dear \_\_\_\_\_

I am a Supervised Postgraduate Research Student in the Department of Nursing Studies at the University of Edinburgh. I am conducting a research study on the hospice movement. The proposed study is an ethnography that will utilise participant observation, and informal interviews with the patients and staff members.

Hospices in the United Kingdom are recognised internationally as providing unsurpassed care to the terminally ill. As a Canadian nurse, my special interest is in terminal care. I intend to return to Canada and resume my nursing career within the field of Palliative Care.

I am writing this letter to request an appointment to discuss my proposed research study, which I am interested in conducting in \_\_\_\_\_. I would be grateful for an opportunity to meet with you and explain and discuss the project. Your advice and suggestions would assist me in the development of the research plan. I shall ring your secretary in the near future to arrange an appointment.

My academic supervisors are Dr A. Faulkner and Dr K. Melia in the Department of Nursing Studies. If you require any further information, please contact me at 667 1011 (Ext. 6668).

Sincerely

Therese Mazer, RN, BN

## APPENDIX II

### Staff Interview Questions

1. How long have you been working at the Hospice?
2. What lead to your working with the terminally ill?
3. What is the 'caring philosophy' of the Hospice?
4. What do the patients mean to you?
5. People keep saying they thought the Hospice is only for terminal patients and that there is only one way to leave the Hospice - dead. For what reasons are patients admitted?
6. When some of the patients arrive they seem uncertain as to where they are and why. What information do they receive on admission? Who provides it?
7. Working with the patients must be emotionally draining for you at times. Where do you receive your support from? What about support from within the Hospice?
8. Many of the patients say they're 'not going home'. Do you know what 'not going home' means? Do you suppose it could mean they've been told they have cancer and are dying?
9. Are there any patients you prefer caring for?
10. Are any patients ever difficult?
11. How would you describe a 'peaceful' death?
12. How would you describe a 'straightforward' death?
13. Are there any other kinds of deaths you have witnessed?
14. Someone said sitting with patients is not working and it is discouraged. Are there any guidelines? What is your personal feeling?
15. Patients in single rooms are very happy with the private bathroom, television, the service and especially the privacy. Like a good bed and breakfast or hotel. Who decides whether a patient is admitted to a private room or ward? Which patients are nursed in wards? Which patients are nursed in singles? Why are patients transferred from a single to a ward? Why are patients transferred from a ward to a private room?
16. There seems to be a difference in patients who remain over, say, a month. Initially they speak of the 'kindness' and 'angels' caring for them. Then the glow seems to wear off. Later their comments are less favourable. Have you noticed this?

17. It can become hectic when several patients are dying. The staff are scurrying about. Is there a policy for caring for a dying patient? How do you decide which patients or families to attend to?
18. What is the procedure for moving a recently deceased patient to the sanctuary? Is it always straightforward? Any difference moving a body from a sideroom?
19. A patient called the Hospice 'millionaires paradise'. What do you think about that?
20. A patient, visitor and some relatives spoke of the deaths in the wards as 'they're popping off like flies'. What would you say if they made the comment to you? What do you think the remaining patients feel?

# APPENDIX III

## Observation Schedule and Hours Worked

Month/date	Scheduled hours	Actual hours	Total
01	19	1300-1700	.50
	21	1200-1600	3.45
	23	0800-1200	3.55
	26	0800-1200	4.00
	28	1200-1600	3.45
	30	0800-1200	4.20
			20.35
02	2	0800-1200W	-
	3	0800-1200	4.15
	5	1200-1600	3.50
	7	0800-1200	4.00
	10	1200-1600	3.10
	12	1200-1600	3.40
	14	1200-1600	3.10
	17	1600-2000	3.30
	19	1600-2000	4.00
	21	1600-2000	4.00
	24	2000-6000	4.00
	26	2000-6000	4.00
	28	2000-6000	4.00
	31	1600-2000	4.55
			50.30
03	8	2300-0700N	-
	9	2300-0700N	-
	12	1500-2300W	7.25
	13	1500-2300	7.35
	15	1500-2300	6.25
	17	1400-1800	3.50
	21	1500-2000	5.00
	23	1500-2000	5.00
	26	1200-1800W	5.45
	27	1600-2200W	5.05
	30	1600-2200	6.05
04	2	0900-1400	3.30
	4-5	2100-0730N	10.40
	7	1400-1800	3.30
	9	0730-1200	4.00
	12	1400-1800	-
	13-14	2100-0730N	-
	16	0900-1200	-
	19	1500-2000	5.00
	22	1500-1900	4.00
	24	1500-1800	3.00
	25	1200-1600	4.00
			37.40



05	9	1600-2000	4.00	
	11	2045-0700N	9.45	
	16	1500-1900	4.00	
	18	1700-2100	4.20	
	20	0900-1300	4.00	
	23	1600-2000	3.45	
	25	1600-2000	4.15	
	27	1500-1900	4.00	
	30	1600-2000	4.00	42.05
06	1	1500-1900	3.50	
	3	1400-1800	4.15	
	6	1500-1900	3.20	
	8	1500-1900	3.20	
	10	1400-1800	2.45	
	13	1500-1900	3.00	
	15	1500-1900	4.45	
	17	1400-1800	-	
	20	1500-1900	3.30	
	22	1500-1900	3.15	
	24	1400-1800	2.00	
	27	1500-1900	-	34.00
07	1	1500-1900	4.20	
	3	1400-1800	3.50	
	13	1500-1900	3.55	
	15	1500-1900	3.45	
	17	1400-1800	3.00	
	20	1500-1900	3.15	
	22	1500-1900	5.35	
	24	1400-1800	4.10	
	29	1500-1900	4.00	
	31	1400-1800	3.45	39.35
08	3	1500-1900	3.50	
	5	1500-1900	4.00	
	7	1400-1800	3.35	
	10	1500-1900	3.20	
	12	1500-1900	4.00	
	14	1400-1800	3.45	22.30
			TOTAL	299.05 hours

#### APPENDIX IV

##### Field Note Extractions

Field note extractions are illustrated with a patient.

O = observation; NA = followed by number signifies a particular nursing auxiliary; numbers following patient's name signifies the ward and bed they were admitted to:

3.10 p.m. O

Bonnie's cubicle (4-4) is cleared out. (She's died?)

O NA-9 in the main hall. I go up to her.

TM 'Bonnie'

NA-9 'Went'

TM 'When'?

NA-9 'Yesterday'.

TM Was her family with her?

NA-9 She went 'during the night'.

I enter into ward 3 and go up to the Neil's. He is a patient.

O They're looking towards the bedside table with a floral arrangement on it. Neil says her husband likes flowers but far away. She says:

He'll get into trouble if he knocks them over'.

I tell him to leave them.

3.40 p.m. In wards 3-4 with Mr Robins. He is expecting a visit from his brother from Saskatchewan, Canada.

TM 'Are you excited about seeing him'?

R 'It may be the last time I see him.

TM 'Is he younger or older than you'?

R 'Older'.

TM 'And how old are you'?

R '50'.

(Time passage)

R 'All the old pensioners are in here'.

TM 'And do you consider yourself one?'

R 'No'.

(Time passage)

TM 'Any deaths in here since Monday'?

R 'Not in this room. Maybe in others, but I don't know about them. None in here'.

(Time passage)

R 'It's actually happening to them. It's not telling lies. It's actually happening to them'.

TM 'What's it like in this room when patients are dying as when they aren't'?

R 'I seen a couple. One in particular. One directly across from me. They did everything possible for him. He was smiling ... not a struggle. It was very peaceful. When mine comes, I'd be very happy' if it's like his. 'Then after it's a little more tragic, when you realise he's gone. I just keep it to myself. It's a strange thing. You sort of feel a sense of loss, even though you're far apart. When it actually happened I just stepped back. His family was in. Then the curtains were drawn'.

(He's speaking so much and fast that my attention is focused on getting it all down rather than supporting him or being able to pick up on several issues within his statement. I wish I had a tape-recorder, for once.)

TM 'Who drew the curtains'?

R 'I think by this time the nurses did. Naturally it's private. There was some crying'.

TM 'Was he dead then'?

R 'Aye. I presumed by this time. The doctor never came in and pronounced. Not being a medical man'.

(Time passage)

'Aye. Just across the bed from me'.

TM 'I think I remember the man'. What about that man?

O I point to B-2

TM The day 'Malcolm' came in.

R 'He got taken out to another ward. I don't know what happened to him'.

The same day that Malcolm arrived, another man was admitted to B-6 and died within 2-3 hours. I tell Mr Robins the same.

R        'If he came in at 4 o'clock he went away' the next 'shift. He was away the same day. He didn't last long'.

TM       'What do you think about those admissions'?

R        'I feel awfully down. If you only see them for a couple of hours. Didn't get a chance. Didn't last long'.

TM       'What are you thinking about the hospice'?

R        'It's a nice place. They go out of their way to make things easier, if at all possible. The folk that work in here are all very decent, obliging. Sometimes I think they do too much for you'.

TM       'Too much of what'?

R        'Too good to you. They're extremely kind and helpful'.

The patient in 3-5 spills tea so I ring the bell. NA-10 arrives and Mr Robins and I stop talking. I lead our discussion to general chat. Then NA-10 leaves the ward.

R        'There is goodness, kindness and greatness. It is here. One moment up and the next down in here'.

TM       'If you can remove yourself from here for one moment, isn't that what life is about'?

R        'Exactly'.

The Hospice Chaplain enters the ward from the Conservatory and goes up to the patient in B3-3 and tells the Neil's that the Chaplain from another Hospice and one of the female General Practitioners visited this Hospice today. I recognised that Chaplain. I listened as the Pastor told the Neil's.

C        Yes he's the Chaplain at \_\_\_\_\_. 'Only two in Scotland. Only full-time Chaplains. We're a rare breed'.

TM       Are you supervising the two Theology students?

C        Yes. One from the New College and 'Bertha' from Germany. I'm 'reporting back to Germany'.

1640 I enter into ward 4-1. Mrs Rogers is usually out on the south of the Conservatory. She is not now.

TM 'Were you out on the conservatory today'?

R Yes. Not long enough. 'They whisked me back'. It's good to get 'out of the wards' and 'see the green'.

(Time passage)

TM 'How long have you been in'?

R 'I came in on the 23 December'.

O NA-10 and S-10 enter ward 4 and begin making up a bed. They talk to me about the opening of a new hospice on the west of Scotland.

NA-10 It's run by the 'Sisters of Charity. It's geriatrics too'.

NA-5 'Like in here'.

TM How many beds?

NA-10 Twenty-six, I think.

NA-5 says the Sisters of Charity are based in Edinburgh.

NA-5 I don't know why they call them that. The place is 'beautiful'. They have everything.

O They are finished making the bed. NA-10 goes to bed 3. NA-5 comes up to me.

TM 'How is it different from here'?

This place is beautiful and they seem to have everything.

NA-5 No. They have everything. I don't understand why they say charity and poor, when they have everything. Nothing is from the 'NHS'.

(I question the staff's reasoning and try to get the staff to the lead that it is beautiful in here.)

I'm on the south Conservatory with a patient from ward 3-4, Mrs Anders. My plan is to interview her about Bonnie's 4-4 death.

TM I'm uncertain which room you're in.

O She motions to ward 4.

A 'Bed 5. The other two died. No one. Every other lady went home'.

TM 'Did Bonnie die'?

A 'Yes she died last night'.

TM Do you know 'if her daughters and granddaughters were with her'?

A 'No dear. It was throughout the night, she died'.

O She looks like she's going to cry. She doesn't look at me. Her hands become shaky.

I drop my intended strategy and silence follows then she says:

A 'There aren't so many visitors today'.

TM 'Also not many patients on the Conservatory'.

O Mrs Anders motions to ward 4.

A 'But'.

TM 'Were you at the Day Hospice today'?

A No. One lady said 'you may as well be here'. They 'were just sitting'. I like 'reading'. 'I'm tired'.

TM Any special reason?

(Like staying awake while her room-mate 4-4 was dying?)

A 'No. One minute you can be tired in here and not so the next'.

I offer to leave her if she's tired. She says her memory isn't good today - evidenced by thinking two died instead of one. I wonder if she's bothered by the deaths. Cannot ask her today.

I'm seated here watching, waiting and hoping that ward 2-2 will be left alone so that I can interview her about Bonnie's 4-4 death. Never do.

O Mey 4-5 when I interviewed and think is upset about the death and is seated right next to her. I don't want Mey to catch on and become upset.

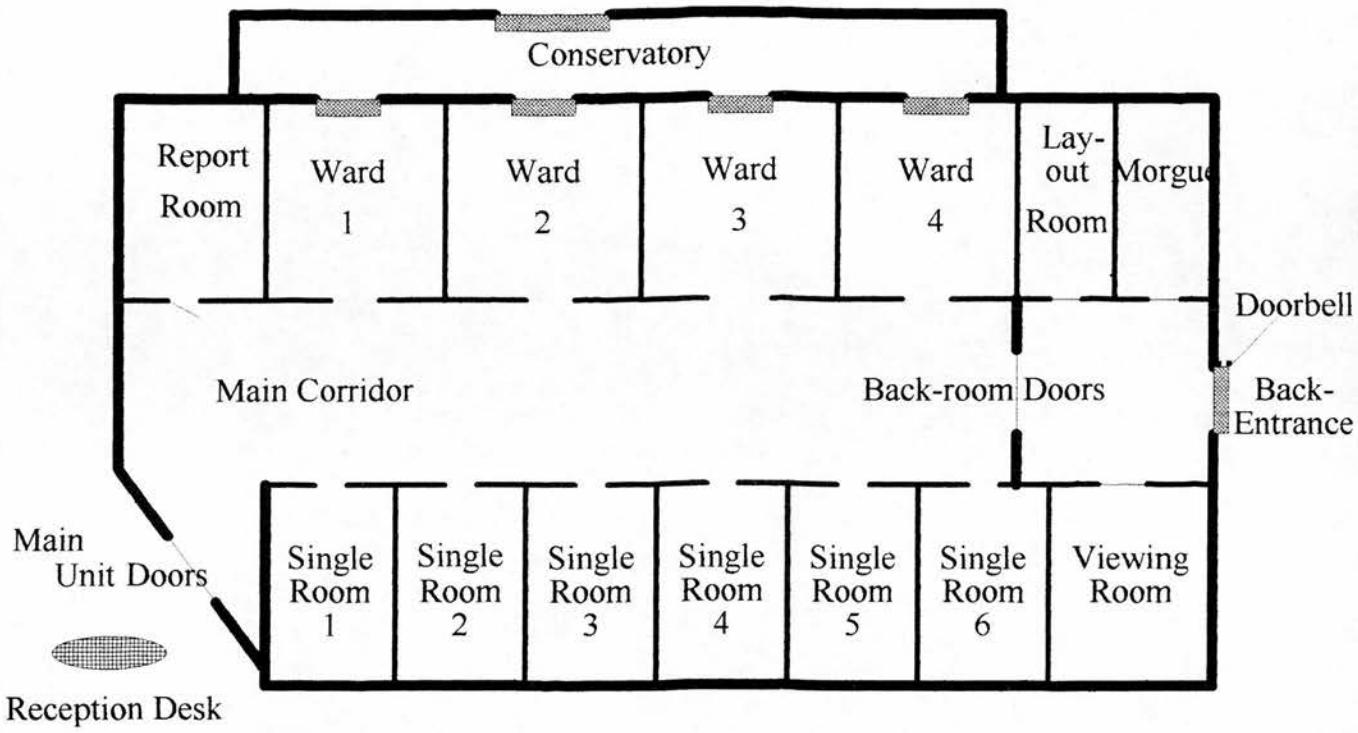
I'm in the change room leaving the hospice as is a Volunteer. Our conversation is about life, people, strangers smiling at you and the possible reactions.

V '... the door's open but you have to walk through it'.

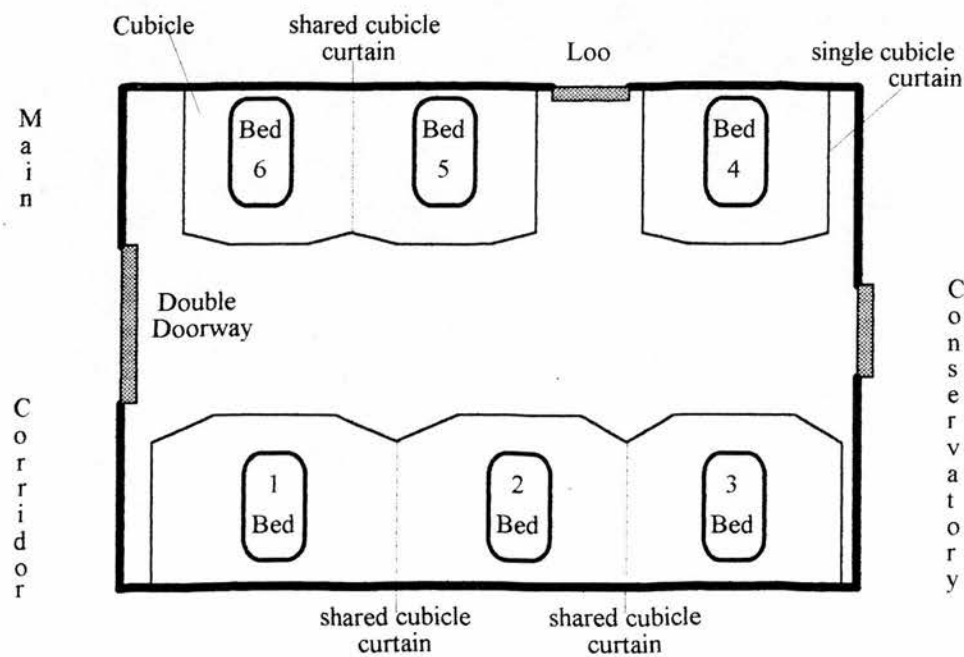
1830 I leave the hospice.

APPENDIX V

Unit Floor Plan



Ward Floor Plan



## REFERENCES



## APPENDIX VI Categories of Patient Participants

Patients were placed into three categories as participants in the research:

Respondents	149
Informants	86
Key informants	33

Respondents were all patients who were spoken to. They answered general questions, unrelated to the study and some declined *any further* participation in it.

Informants offered information and answered my questions about deaths.

Key informants offered information about deaths that occurred, especially those in my absence from the hospice. Key informants were educated to understand what kind of information I was interested in obtaining.

**APPENDIX VII Statistics on Patient Throughput in the Hospice**

1988 :

Admissions 478

Discharges 126

Deaths 350

1989 :

Admissions 500

Discharges 152

Deaths 348

**Average Length of Stay**

1988 17.6 days

1989 18.91 days

**Range of Stay**

3 hours - 77 days

APPENDIX VIII Nursing Staff on the In-patient Unit

Nursing Sister	1
Junior Nursing Sister	3
Trained Staff Nurses	22
Nursing Auxiliaries	32

Average staff types and numbers per shift

7.30 a.m. - 4.0 p.m.

1 Senior Sister  
7 Staff Nurses  
6 or 7 Nursing Auxiliaries

1.0 p.m. - 9.15 p.m.

1 Junior Sister  
2 or 3 Staff Nurses  
3 Nursing Auxiliaries

8.45 p.m. - 7.30 a.m.

1 Junior Sister or full-time Staff Nurse  
2 part-time Staff Nurses  
3 or 4 Nursing Auxiliaries

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